AN INTEGRATED PROCESS MODEL FOR SOCIAL MEDIA APPROPRIATION BY CHRONICALLY ILL ADULTS

Nwakego Ugochi Isika
ORCID: 0000-0003-1601-2930

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Melbourne School of Engineering
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Keywords

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Abstract

Social Media Technologies (SMTs) have had a considerable impact on society: as platforms for activism; as support for new business models and; to organize people around common causes such as health. Moreover, according to the World Health Organization, chronic illness currently accounts for 63% of deaths globally. This number is estimated to rise to between 73%-79% of global mortality by the year 2020. Consequently, several scholars have begun to examine SMT adoption and use to manage one's health and well-being. However, the focus of studies on SMTs for managing one’s health have been on motivation mechanisms and overlooked the appropriation context and process. As a result, there is a fragmented picture and limited theoretical insights on the processes of appropriation of SMTs.

This study poses and addresses the research question: How do chronically ill adults appropriate social media tools to better understand and manage their illness? The present study addresses this question through a multiple case study with mixed methods. This study examined four social media tools (Reddit, YouTube, Instagram and Facebook) with different features and capabilities to derive an integrated theoretical insight on SMT appropriation in the chronic illness context. Based on theoretical insights derived from this study, this work presents a new process model for appropriation of SMTs, a framework on influences that support or discourage appropriation of SMTs and outlines a set of unique affordances supported by SMT technology features that enable or disrupt illness management. Further, this work provides a set of propositions to guide the application and design of SMTs for key stakeholders including healthcare SMT designers, general practitioners and chronically ill adults.
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<td>ESM</td>
<td>Enterprise Social Media</td>
</tr>
<tr>
<td>ESN</td>
<td>Enterprise Social Network</td>
</tr>
<tr>
<td>IS</td>
<td>Information Systems</td>
</tr>
<tr>
<td>LDA</td>
<td>Latent Dirichlet Allocation</td>
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<tr>
<td>MTA</td>
<td>Model of Technology Appropriation</td>
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<td>SMT</td>
<td>Social Media Technology</td>
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<td>SST</td>
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List of publications from this thesis


Statement of original authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signature: __________________________

Date: ___________7th of June 2019________________
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Chapter 1: Introduction

Social media technologies have had a considerable impact on society acting as platforms for activism; support for new business models and to organize people around common causes such as health (McKenna et al. 2017; Rozenblum and Bates 2013; Urquhart and Vaast 2012). Accordingly, today a growing number of chronically ill adults make use of social media technologies to better understand and manage their illness. Recent studies have highlighted the growing global burden of chronic diseases such as diabetes or cancer due to biological and preventable lifestyle factors such as increased sedentary living and an ageing population (Bodenheimer 2002; Georgeff 2014). Furthermore, a recent report by the World Health Organization (WHO 2016) states that currently 60% of deaths globally are due to chronic disease and these figures are expected to rise to 73% of all deaths regardless of socio-economic class by 2020. In fact, according to that report, the projected increase in chronic illness related to mortality for developing nations is 79% of all deaths (Department of Health & Human Services 2016; WHO 2016). Hence, scholars have suggested that technologies such as social media could serve as a cost-effective tool in self-management of chronic illness. This suggestion is in line with the care plan proposed in variations of the chronic care model which act as a guide for stakeholders such as general practitioners and other healthcare service providers to improve patient involvement and empowerment in managing chronic conditions (Kreindler 2009; Wagner 1998; Yach et al. 2004).

It appears that prior studies conducted on social media use for health are focused on motivation mechanisms, incentives/reasons for adoption of Social Media Tools (SMT) for health related needs as potential influences on SMT appropriation for chronic illness management (Chung 2014; Hajli et al. 2014; Pousti et al. 2014; Wang et al. 2017). In addition, recently studies in this area have started to focus on affordances that arise from appropriation of SMTs for illness management as health related outcomes (Bernardi 2016; Coulson et al. 2017; Merolli et al. 2013a). Consequently, this class of studies has taken a blackbox view of SMT technology environment and have overlooked the processes of appropriation of SMT within the public context to manage one’s health and wellbeing (Agarwal et al. 2010; Fichman et
al. 2011; Merolli et al. 2013a). To this effect, there has been limited empirical investigation into how SMTs are utilized by these individuals to better understand and manage their chronic illness. Hence, it is necessary to further explore how social media tools are used to gain a more in-depth insight into potential benefits or drawbacks of these tools in the context of chronic illness self-management.

The purpose of this research therefore, is to gain a deeper understanding of how adults with chronic illnesses engage with or appropriate social media tools to better understand and manage their illness.

1.1 RESEARCH CONTEXT AND SIGNIFICANCE

Information Systems (IS) scholars have long been concerned with investigating how various technologies have been adopted, adapted and used with the aim to theorize the impacts of technology across various usage contexts (Al-Natour and Benbasat 2009; Christophe et al. 2011; Nevo et al. 2012; Schmitz et al. 2016; Shaikh and Karjaluoto 2015). In general, scholars have suggested that appropriation is an emergent process influenced by the user, their social environment and their need/goal (Beaudry and Pinsonneault 2010; Mendoza et al. 2010). These studies suggest that appropriation is contextual, and may be faithful or unfaithful depending on the needs of the user of a given technology artefact (DeSanctis and Poole 1994; Mudambi et al. 2016). Also, some recent studies have illustrated that the choices involved in the appropriation of an IT artefact are often motivated by the user’s emotions during this process (Mendoza et al. 2013; Stein et al. 2012). The present study takes a holistic view of appropriation that includes the environment provided by technology (social media), the tasks of the user and the processes undertaken by the user to accomplish their tasks within this technologically mediated environment.

1.1.1 Related studies on social media in information systems scholarship

Social Media Tools (SMT) is defined as: ‘‘a group of Internet-based technologies that allow users to easily create, edit, evaluate and link to content or other creators of content’’ (Kaplan and Haenlein 2010). These SMTs are socio-technical systems which have attracted significant research interest from scholars across various disciplines including IS. SMTs enable users to participate, produce and consume content while interacting with their peers through a technologically mediated environment, forming connections which may not be limited by geographical location
These studies have reported numerous influences on appropriation such as: familiarity, ease of use, usefulness, altruism, demographic factors such as gender/age, hedonic factors such as enjoyment, self-presentation and many others (Ellison et al. 2010; Riemer and Johnston 2012; Subramaniam et al. 2013; Treem et al. 2015). For instance, Rauniar et al. (2014) applied the Technology Acceptance Model (TAM) to investigate the adoption of Facebook among student cohorts using a survey methodology. Their study found that use of Facebook correlated with utilitarian constructs such as perceived usefulness, perceived trustworthiness, perceived ease of use and hedonic constructs such as perceived playfulness that could determine intention to use and actual use behaviour among their respondents.

In contrast, Hsu and Lin (2008) applied the Theory of Reasoned Action (TRA) to investigate motivations for using blogging SMT in Taiwan to share knowledge. Their study found that perceived usefulness was not significantly related to intention to use, rather hedonic factors such as enjoyment, ease of use and individual factors such as altruism influenced acceptance and continued use of blogging social media tools (Hsu and Lin 2008). These conflicting results indicate that influences on appropriation outcomes are context specific, relative to an actor in an environment. In this study, influences comprise attributes of the technology artefact such as ease of use or usability and individual incentives/motivations for adoption such as need for social support.

Although there have been numerous studies on influences for adoption or use of an SMT, very few studies have examined the processes involved in appropriating these SMTs. Instead, studies in this context have applied variance theories or sociomateriality to investigate how SMTs are used by different cohort to accomplish their tasks. Variance theories such as Uses and Gratifications Theory (UGT) or Technology Acceptance Model (TAM) in this context have historically viewed intention to use instead of actual interactions with IT leading to very high level descriptions on how SMTs are applied by various cohorts to accomplish their tasks (McKenna et al. 2017; Urquhart and Vaast 2012). Another stance that has led scholarly investigations in the social media context is the sociomaterial perspective suggests that digital technologies are tightly embedded into the fabric of local practices and continuously in a re-making process. Some scholars suggest that during the
appropriation of social media, users may perform embodied identity (Schultze 2014; Schultze and Orlikowski 2010) or co-produce value (Alaimo and Kallinikos 2017) through sociomaterial entanglements. However, a significant shortcoming of this sociomaterial bent lies in its highly localized theoretical insights which are focused on snapshots of idiosyncratic appropriations (Gaskin et al. 2014). As a result, sociomaterial studies on appropriation lack the ability to offer practical insights that may inform the design of SMTs for specific use contexts and lack of generalizability to inform theory in other use contexts.

Further, some other scholars suggest that the process of appropriation occurs in phases, in a bottom-up manner; for instance, Riemer and Johnston (2012) examined the appropriation of Yammer using genre analysis with data scraped from the site. They suggested that appropriation of Enterprise Social Media (ESM) is phased, bottom-up and involved collective sensemaking by users in that context (Riemer et al. 2012; Riemer and Johnston 2012). However, the study did not solicit primary data from users in the organization nor further unpacked the process of appropriation of social media.

1.1.2 Social media and health related studies

Chronic diseases are complex non-curable medical conditions with prolonged implications on sufferers and their communities (Pousti and Burstein 2014). Effective chronic illness management requires the patient to engage in daily practices in order to achieve better physical and psychological health outcomes (Bodenheimer 2002; Schulman-Green et al. 2012). Cohort studies indicate that these social media technologies have robust appropriation mechanisms such as exchange of emotional, physical and informational support in the health context, particularly among chronically ill individuals (Fichman et al. 2011; Wang et al. 2017). As a result other scholars have examined SMT use in the healthcare context as: motivation mechanisms that influence adoption (Ba and Wang 2013); in the creation of social value (Goh et al. 2016) and outcomes in terms of social support (Coulson 2005; Guo and Goh 2014; Mo and Coulson 2010; Wang et al. 2017); or as therapeutic affordances (Merolli et al. 2015).

Overall, these studies suggest that technologies such as social media could augment health management practices of chronically ill cohorts by providing an opportunity for patients to self-manage their illness (Bender et al. 2013; Hajli 2014;
Merolli et al. 2013). Since healthcare services and providers typically provide episodic care for illness; developing an illness-management practice is essential for chronically ill adults, and SMTs could be considered a useful set of tools available to these individuals for self-management of their illness (Liang and Xue 2013). SMTs present chronically ill users with an opportunity to gain information and engage in interactions that have ramifications on their physical and mental health (Fernández-Luque and Bau 2015). However, Chung (2014) argues that despite the extensive literature in the domain, little is known about how individuals use these technologies for self-management of their conditions. Chung (2014) suggests that usage patterns could impact the outcomes obtained from using the technology. In addition, several studies suggest that changes in the features and functionalities of systems could impact the benefits obtained by using social media and the processes undertaken by users to apply these SMTs to their illness-related activities (Agarwal et al. 2010; Bernardi and Wu 2017; Chung 2014; Dadgar and Joshi 2018; Merolli et al. 2015).

Taken as a whole, it seems despite the potential benefits of SMTs to aid in the growing burden of chronic illness; there is limited theoretical insight about how chronically ill individuals utilize SMTs for their illness management practices. For instance, scholars argue that there has been little investigation in terms of: (1) who are the users of these social media tools and (2) how these technologies are applied to better understand and manage chronic illness (Agarwal et al. 2010; Fernández-Luque and Bau 2015; Fichman et al. 2011; Goh et al. 2016). Also, given that chronic illness has long term ongoing physical and psychological repercussions for sufferers, little attention has been given to the emotional motivations for appropriation of social media by these individuals.

Due to the limitations highlighted briefly in the preceding sections and more extensively in Chapter 2, this thesis extends existing knowledge through an empirical investigation of social media appropriation by chronically ill adults. In particular, this thesis examines how and to what extent four different social media tools: Reddit, YouTube, Instagram and Facebook; are appropriated by chronically ill individuals to better understand and manage their illness. Several scholars have given varying definitions of the concept of appropriation. For instance, DeSanctis and Poole (1994) defined appropriation as the way a group uses, adapts and reproduces the structures of technology based on their needs (DeSanctis and Poole 1994). On the other hand,
Mifsud et al. (2015) explained appropriation as the activities that a user carries out to bring technology into their practices to create their own sense of the technology to accomplish their desired task (DeSanctis and Poole 1994; Mifsud et al. 2015).

For this thesis, appropriation is defined as: “the way that users evaluate and adopt, adapt and integrate a technology into their everyday life” (Carroll, Howard, Peck, et al. 2002; Mendoza et al. 2010). Also, this study takes a holistic view of appropriation that includes the environment provided by the technology, the task of the user and the processes undertaken by the user to achieve his/her task within this technologically mediated environment.

Further, this present work is designed as a multiple case study with convergent mixed methods to provide an integrated model for social media appropriation by chronically ill adults. The resulting findings and interpreted knowledge derived from this study was then harnessed to develop a new integrated process model to describe and explain social media appropriation by chronically ill adults to better understand and manage their illness (self-management). Also, findings from this thesis provide a new framework to address supporting and discouraging influences on appropriation of SMTs for chronic illness management. Our findings also contributed a set of affordances stemming from the technological features of SMTs which enable or disrupt appropriation of SMTs for chronic illness management.

1.1.3 Aim and scope of this research

This thesis aims to gain a deeper understanding of how adults with chronic illnesses engage with or appropriate social media tools to better understand and manage their illness. Accordingly, this work focused on chronically ill adults with fibromyalgia with a focus on how they appropriated SMTs as part of their daily illness management practices.

Knowledge derived from this multiple case study with mixed methods is developed into three main outcomes:

- A new integrated process model for social media appropriation by chronically ill adults;
- A framework which describes the supporting or discouraging influences on appropriation of social media for chronic illness management;
• A set of affordances which enable or disrupt appropriation of SMTs in order to gain deeper insights into managing chronic illness, and

1.2 RESEARCH APPROACH AND DESIGN

In particular, this thesis takes an interpretive research approach to address the following main research question:

*How do chronically ill adults engage with and appropriate social media tools to better understand and manage their illness?*

Accordingly, the following sub-questions are posed and addressed in this thesis:

1. What are the processes undertaken by chronically ill adults to appropriate social media as part of their illness management practices?

2. What factors influence appropriation of social media tools by chronically ill adults? and,

3. How do social media technology features enable or disrupt illness management practices of chronically ill adults?

This study’s creative multiple case design aims to address the research questions posed above. Moreover, this study specifically focused on four different SMTs based on their features and to represent different technology core capabilities: 1) Reddit (text-based); 2) YouTube (video-based), 3) Instagram (photo-based); and 4) Facebook (hybrid) as sites for the multiple case study.

Four case studies were conducted in parallel and analysed through a cross-case synthesis. Insights obtained from the multiple case study include case-specific themes and general themes to address the study questions outlined above (Eisenhardt 1989; Miles et al. 2014; Walsham 1995; Yin 2013). The analysis applied to this study used interpretive research approaches to explicate the processes, influences and affordances which act as enablers or disruptors for social media appropriation by chronically ill adults for their illness management practices (Gioia et al. 2013; Neuman 2006; Walsham 1995). A more extensive discussion of the research design is provided in Chapter 3.
1.3 OVERVIEW OF RESEARCH CONTRIBUTIONS

This thesis extends existing knowledge on technology appropriation and addresses the numerous calls for research on social media use in the context of chronic illness management (Agarwal et al. 2010; Chen 2017; Fernández-Luque and Bau 2015; Fichman et al. 2011). In contrast to most previous work conducted by IS scholars on social media use, it not only outlines the influences on appropriation of these SMTs for chronic illness management but also provides the unique processes that explain how these SMTs are utilized during illness management practices of these chronically ill adults. In addition, this study also presents the set of affordances that act as enablers and disruptors to appropriation of social media by chronically ill adults. Furthermore, counter to most technology appropriation studies, this study further extends IS examination outside the ‘organizational container’ to appropriation by users in the public context, where adoption is voluntary (Winter et al. 2014; Yoo 2010).

The main contribution of this thesis is a new integrated process model for social media appropriation that provides new insights into the appropriation processes of chronically ill adults utilizing social media in their daily illness management practices. In addition, this thesis presents a new framework for the influences on appropriation that explicates the supporting and discouraging factors which impact the appropriation of SMTs by chronically ill individuals. Finally, this thesis also outlines a set of enabling or disruptive affordances for chronic illness provided by SMT technology features.

1.3.1 Contributions of the research

This study extends technology appropriation literature because it builds on the existing Model of Technology Appropriation (MTA) to:

1. Present a new integrated process model which explains the processes of appropriation for chronically ill individuals in a social media environment.
2. Provide a new framework that outlines factors that support or discourage social media appropriation by chronically ill adults.
3. Outlines a set of affordances from social media technology features that enable or disrupt the illness management practices of chronically ill individuals.
4. Provide a set of ten propositions derived based on the findings from this study to advance theoretical understanding on appropriation of social media in the context of chronic illness management.

In addition, the practical contributions of this study are briefly outlined below:

1. Provides actionable insights into the potential applications of SMTs to enhance care delivery for chronically ill adults.

2. Provides an outline to facilitate further involvement of GPs and other caregivers for the day to day practice of chronic illness self-management.

3. Outlines the benefits and risks that arise from the use of different social media tools to inform the self-management practice for chronically ill adults.

4. Provides a needs-based assessment and comparison to assist self-selection of SMTs for self-management of chronic illness.

A more comprehensive discussion and explication of these contributions are provided in Chapters 9 and 10 respectively.

1.4 THESIS OUTLINE

The subsequent chapters in this thesis are organized as follows:

Chapter 2 assesses related research from the health domain, specifically how patients’ use of social media has been evaluated by scholars. Induced research gaps are highlighted and the need for further research on technology appropriation is highlighted based on these gaps. Chapter 2 concludes with a conceptual model derived from the interpretation of the studied literature in relation to the research question of the study.

Chapter 3 describes the research design, paradigm and methods that frame the conduct of this thesis. In addition, the dominant research paradigms in information systems are evaluated and the main approaches for conducting research within information systems are also evaluated, and the chosen research approach for the study is outlined. Also, ethical considerations that guided this study are delineated.

Chapter 4 outlines key findings from the Reddit case study, demarcated into four main categories: individual motivations, environmental influences; the process of appropriation and enablers/disruptors to the process of appropriation.
Chapter 5 presents key findings from the YouTube case study that are demarcated into four main categories: individual motivations, environmental influences; the process of appropriation and enablers/disruptors to the process of appropriation.

Chapter 6 describes key findings from the Instagram case study that are demarcated into four main categories: individual motivations, environmental influences; the process of appropriation and enablers/disruptors to the process of appropriation.

Chapter 7 presents key findings from the Facebook case study demarcated into four main categories: individual motivations, environmental influences; the process of appropriation and enablers/disruptors to the process of appropriation.

Chapter 8 draws on the results of Chapters 4 to 7 to synthesize general and unique findings across all cases to derive a better understanding and explanation on how different types of social media tools are appropriated by chronically ill adults.

Chapter 9 reflects on the full study and the work done in relation to the guiding research questions. First, Chapter 9 discusses how the present work extends the fundamental MTA model and practice lens applied to the study. Findings from this study are discussed extensively in Chapter 9 culminating in presentation of: 1) a new integrated process model for appropriation of social media tools by chronically ill cohorts; 2) a framework on influences of appropriation for chronically ill adults and; 3) a set of SMT technology affordances that enable and disrupt the illness management tasks of chronically ill adults. Chapter 9 also contains ten propositions that were induced by this study and discussed further in Chapter 9.

Chapter 10 concludes the thesis by summarizing the contributions of this study to theory and practice. Additionally, Chapter 10 outlines the limitations of the study, research implications, and highlights future research directions as part of the conclusion to this study.
Chapter 2: Theoretical background

INTRODUCTION

The previous chapter provided an overview to the study context, and the extent of the research conducted to address the research question of this thesis: *How do chronically ill adults engage with and appropriate social media tools to better understand and manage their illness?* This Chapter 2 expands on that context to provide an assessment of related literature and aims to provide the theoretical underpinnings for this study based on 1) technology appropriation; 2) social media and; 3) chronic illness self-management. First, Section 2.1 presents an overview of key terms and definitions relevant to the study context. Next, Section 2.2 outlines the literature review methodology, applied to this Chapter. Subsequently, Section 2.3 provides a synthesis of the evolving scholarly discourse on technology appropriation. Next, Section 2.4 evaluates related studies for influences on adoption and use of IT. After that, Section 2.5 assesses related studies on the process technology appropriation reported in similar studies. Following that, Section 2.6 summarizes our review, highlights limitations in knowledge and provides the practice lens that guides the research. This Chapter then concludes with a summary in Section 2.7.

2.1 KEY TERMS AND DEFINITIONS

The following section outlines terms commonly used in this context and their definitions.

**Adoption:** adoption refers to a user’s decision to either accept or reject a given technology; adoption studies have two dominant perspectives: either from the perspective of acceptance in a generalized sense or from the perspective of acceptance and integration into a technology use context (Al-Natour and Benbasat 2009; Karahanna et al. 1999).

**Adaptation:** Technology adaptation has been coined to explain the cognitive and behavioural adjustments by users over time to cope with changes within a given technology system (Abbott et al. 2015; Beaudry and Pinsonneault 2001; 2005; 2010). The process of adaptation is constrained by pre-existing organizational structures,
tasks and social structures within work groups (DeSanctis & Gallupe 1987; DeSanctis & Poole 1994; Maznevski & Chudoba 2000).

**Affordances/constraints:** The concept of affordances was posited by Giddens (1976) in the perceptual psychology field, in his seminal work on how an organism adapts to and understands their environment in terms of form, function and perceptions of goal-oriented actions (Bloomfield et al. 2010; Chemero 2003; Fayard and Weeks 2014; Gaver 1991; Norman 1999; Withagen et al. 2012). In information systems, this theory has been adapted to conceptualize the action potential the features of a technology offer to a user to enable (afford) or disrupt (constrain) achievement of their goals (Faraj and Azad 2012; Leonardi 2017; Majchrzak et al. 2013; Majchrzak and Markus 2012; Volkoff and Strong 2013).

**Appropriation:** The word appropriation derives from the Latin word ‘appropriare’ or ‘appropriationem’ and is defined in Meriam Webster’s dictionary as “setting apart or taking for one’s use”. It is also defined as “making something one’s own”. Appropriation has also been defined as the processes or adjustments that occur between system adoption and adaptation over time (Mendoza et al., 2010).

**Chronic diseases/illness:** Chronic illness refers to health conditions that last longer than three months in duration and these often persist for an entire lifetime (Dadgar and Joshi 2018; Department of Health 2012; Romanow et al. 2012). According to a recent report by the World Health Organization (WHO), chronic diseases are the leading cause of mortality worldwide. WHO estimates that by 2020 the deaths resulting from chronic illness will account for 73% of all deaths in developed nations and 79% of all deaths for developing nations (Department of Health & Human Services 2016; WHO 2016).

**IT artefact:** The application of technology to enable some tasks within a context/structure (Benbasat and Zmud 2003). Some studies have defined IT artefacts as configurations or bundles of hardware and software features that constitute an information technology (Orlikowski and Iacono 2001). In this study the term technology artefact comprises the features of the technology and encapsulates user interface concepts.

**Materiality:** The physical constitution of technological objects (or lack of it) and the implications (social and technical) that these have for creating, design, and use
of such objects (Kallinikos 2002, 2012). The notion of materiality also refers to the arrangement of an artefact’s physical and digital materials into particular forms that endure across differences in place and time and are essential to users (Alaimo and Kallinikos 2017; Kallinikos et al. 2012; Leonardi 2012).

**Technology use**: In this study ‘use’ is defined as the behaviours a user employs in order to make use of an IT artefact for their practices (Walsh et al. 2016).

**Self-management/illness management**: Self-management is a daily, dynamic, interactive practice carried out with the involvement of family, friends, healthcare professionals and other concerned members of the community. Self-management addresses a patient-centred care approach that shares responsibility for ongoing management of chronic conditions with the ill individual (Bodenheimer 2002; Dadgar and Joshi 2018; Greenhalgh 2009; Househ et al. 2014).

**Social media**: Synonymous with the term web 2.0, social media are commonly defined as a set of internet-based, interactive computer-mediated technologies or tools that facilitate the creation and exchange of user-generated content (Kaplan and Haenlein 2010; Kietzmann et al. 2011; Ngai et al. 2015). This term comprises several types of technologies ranging from bookmarking sites such as digg.com to rich media sites such as SecondLife which offer a fully immersive virtual experience to users.

**Online communities/Online social networks**: The terms online communities and online social networks are used interchangeably in the literature to refer to digitally-enabled virtual communities comprised of individuals connecting for a common cause or sharing the same practices (Johnson et al. 2010; Kane et al. 2014; Ngai et al. 2015; Ngai et al. 2015). Online communities enable users to participate, produce and consume content and form virtual connections which may not be limited by geographical location or boundaries (Berger et al. 2014; Boyd and Ellison 2007; Faraj et al. 2016; Johnson et al. 2010).

### 2.2 LITERATURE REVIEW METHODOLOGY

According to Webster and Watson (2002), “*Information systems is an interdisciplinary field straddling other disciplines, you often must look not only within the IS discipline when reviewing and developing theory but also outside the field.*” (Webster and Watson 2002). First, the selection strategy followed the steps recommended by Wolfswinkel et al. (2013) which included 5 steps: 1) Defining the
topic of interest; 2) Searching through peer-reviewed sources for relevant articles; 3) Selecting appropriate literature from the search results; 4) Analyzing selected articles and; 5) Presentation of findings based on key concepts. Next, using the methodology proposed by Webster and Watson (2002), the researcher conducted searches on scholarly databases such as ABI/INFORM, ProQuest and Google scholar for peer-reviewed conceptual, empirical and reviewed articles related to the study domains.

Because several different terms are used to categorize research articles in this context, it was necessary to perform Boolean searches using related keywords, for example: “social media OR social network OR social network site OR online community”. Also, other scholars who were aware of the study topic suggested related peer-reviewed articles for inclusion in the review (vom Brocke et al. 2015; Webster and Watson 2002). The set of articles selected for review were purposively sampled based on a reading of the abstracts and conclusions of the research article to filter for relevance (Bandara et al. 2011; Wolfswinkel et al. 2013). Next, backwards and forwards search was performed to identify related studies based on the initial set of articles that had been retrieved for inclusion in the review (Webster and Watson 2002).

Finally, this research applied a concept-centric approach to the synthesis of the selected literature as advocated by numerous IS scholars who suggest related studies should be systematically categorized around related themes and concepts (Bandara et al. 2011; Schryen 2015; Webster and Watson 2002; Wolfswinkel et al. 2013). The next section addresses the evolving definitions of technology appropriation by IS scholars.

2.3 THE EVOLVING DISCOURSE AROUND TECHNOLOGY APPROPRIATION AND SOCIAL MEDIA

Studies on technology appropriation have been conducted under several blanket terms such as reinvention; adaptation; drift; appropriation, adjustment and alignment (Abbott et al. 2015). As illustrated Table 2.1 below, these class of studies are focused on the relationships between users, technology or task (Abbott et al. 2015) to investigate how technology use leads to specific outcomes in different organizational contexts (Bostrom et al. 2009). Recently, IS scholars have called for more research into other contexts than the traditional organization-oriented focus that has dominated IS scholarship since its inception (Alaimo and Kallinikos 2017; Kallinikos et al. 2013; Yoo 2010).
<table>
<thead>
<tr>
<th>Number</th>
<th>Author</th>
<th>Term</th>
<th>Term definition</th>
<th>Focus</th>
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<tbody>
<tr>
<td>1</td>
<td>Rice and Rogers (1980)</td>
<td>Reinvention</td>
<td>The degree to which an innovation is changed by the adopter in the process of adoption and implementation</td>
<td>Technology</td>
</tr>
<tr>
<td>2</td>
<td>Leonard-Barton (1988)</td>
<td>Adaptation</td>
<td>The modification of the technology and the simultaneous adaptation occurring at multiple levels within the organization</td>
<td>Technology, Work system</td>
</tr>
<tr>
<td>4</td>
<td>DeSanctis and Poole (1994)</td>
<td>Appropriation</td>
<td>The way a group uses adapts and reproduces the structures of technology based on their needs.</td>
<td>Technology, Work system</td>
</tr>
<tr>
<td>5</td>
<td>Tyre &amp; Orlikowski (1996)</td>
<td>Adaptation</td>
<td>Changes brought to the technology, working system and users’ views following an IT event.</td>
<td>Technology, Work system, User</td>
</tr>
<tr>
<td>6</td>
<td>Orlikowski (1996)</td>
<td>Appropriation</td>
<td>The adaptations and adjustments enacted over time which transforms practice and the structure: The continuous, progressive, and mutual adjustments, accommodations, and improvisations between the technology and the users</td>
<td>Technology, User</td>
</tr>
<tr>
<td>7</td>
<td>Majchrzak et al. (2000)</td>
<td>Appropriation</td>
<td>Appropriations, which may be subtle and difficult to observe, are defined as the immediate, visible actions that evidence deeper structuration processes</td>
<td>User</td>
</tr>
<tr>
<td>8</td>
<td>Dourish (2003)</td>
<td>Appropriation</td>
<td>The way technologies are adopted, adapted and incorporated into working practice. Appropriation might involve customization/explicit reconfiguration of the technology in order to suit a user’s needs, or it might involve making use of the technology for purposes beyond those for which it was initially designed, or to serve new ends.</td>
<td>Technology, Work system, User</td>
</tr>
<tr>
<td>9</td>
<td>Beaudry &amp; Pinsonneault (2005)</td>
<td>Adaptation</td>
<td>Focuses on user cognitive and behavioural adaptation responses and accounts for a wide range of user behaviours such as technology appropriation, avoidance, and resistance.</td>
<td></td>
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<td></td>
<td>Author(s) and Year</td>
<td>Concept</td>
<td>Description</td>
<td>Components</td>
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<tr>
<td>10</td>
<td>Carroll et al. (2007)</td>
<td>Appropriation</td>
<td>The way that users evaluate and adopt, adapt and integrate technology into their everyday practices</td>
<td>Technology, Task, User</td>
</tr>
<tr>
<td>11</td>
<td>Mendoza et al. (2010)</td>
<td>Appropriation</td>
<td>Involves both adoption and adaptation of technology over time by a user in a context to fulfil specific tasks</td>
<td>Technology, Task, User</td>
</tr>
<tr>
<td>12</td>
<td>Ortiz de Guinea and Webster (2013)</td>
<td>IS use pattern</td>
<td>An IS use pattern is a group of emotions, cognitions, and behaviours that occur together, and whose values change together in response to events in the user’s environment in response to a technology event.</td>
<td>Technology, Task, User</td>
</tr>
</tbody>
</table>
2.3.1 Conceptualizing Social media

Social Media Tools (SMTs) are commonly defined as: “a group of Internet-based technologies that allows users to easily create, edit, evaluate and link to content or other creators of content” (Kaplan and Haenlein 2010). Several terms are used in the literature to describe SMTs such as social technologies, social computing, Web 2.0 and others. The term “social media” includes technologies such as blogs, video-sharing sites, micro-blogs, forums, websites, virtual worlds or wikis created to facilitate virtual interaction by users and creation of user-generated content (Kane et al. 2014; Kaplan and Haenlein 2010; Kietzmann et al. 2011). Several characteristics differentiate social media from older technologies: user-generated content, peer-to-peer communication, networking, multimedia-orientation and user-friendliness (Kane et al. 2014; Majchrzak et al. 2013; Panahi et al. 2012). Figure 2.6 below illustrates the different levels of immersion provided by the different categories of social media tools.

![Figure 2.1 Social Media Tools and Technologies categorized by level of interaction/immersion (Adapted from Ngai et al. 2015)](image)

Furthermore, social media systems in the public context are continually evolving around a set of core elements, with emerging features (Alaimo and Kallinikos 2017; Spagnoletti et al. 2015; Yoo 2010). As a result, social support, financial gains, knowledge and innovation are facilitated on a global scale (Agarwal et al. 2008; Choy and Schlagwein 2016; Leong et al. 2016; Orlikowski and Scott 2015; Vaast et al. 2017).

2.3.2 Social media use in the context of chronic illness self-management

Several studies have argued that SMTs have a role to play to alleviate some of the challenges involved in managing chronic illness. These challenges include personal repercussions from being chronically ill against the backdrop of struggling healthcare services that are ill-equipped to provide long-term care for individuals with chronic illness. Although scholars in the healthcare sector have been conducting studies into the influences and potential benefits of online community membership, the majority of existing studies have been carried
out on the predecessors of social media such as discussion boards, forums and chat rooms (Merolli et al. 2015; Patel et al. 2015).

Moreover, healthcare scholars have focused on the mechanisms/personal factors such as emotional support exchanges, and social, supportive exchanges that motivate adoption and use of SMTs by chronically ill adults. As a result, they have overlooked environmental influences from the SMT on adoption for chronic illness management. Further, with the notable exception of the study by Chung (2014), the processes of use have been overlooked in these studies. Even so, that study was conducted on an older technology—a discussion board. Because the healthcare sector is better equipped to provide episodic care for chronically ill patients, some scholars argue that SMTs could serve as a valuable source of some aspects involved in self-management of chronic disease (Bernardi 2016; Merolli et al. 2015; Pousti et al. 2014; Wang et al. 2017).

Given the high attrition rates that are ascribed to custom-built health SMTs in the healthcare sector, it is crucial to gain a complete understanding of the technologies that are being appropriated and derive transferable insights to guide the design of illness management SMTs (Dadgar and Joshi 2018). The following section reviews related theories that have been applied by IS scholars on technology appropriation.

2.3.3 Overview of commonly applied theories in seminal studies of appropriation

An engagement with IS appropriation literature identifies two main categories of theories used; variance theories and process theories as outlined in the sections that follow.

1.) Variance theories in IS studies on appropriation

The Theory of Reasoned Action (TRA) was proposed by Fishbein and Ajzen (1975) and posits that an individual’s behaviour can be predicted by an examination of his/her intentions, attitude and the subjective norms associated with technology use (Ajzen and Fishbein 1975; Venkatesh et al. 2003). Figure 2.1 below illustrates the relationships between constructs in the authors’ initial version of TRA. TRA studies have been useful to empirically demonstrate the perceived influences that usefulness, ease of use and other similar constructs have on the acceptance and usage of technology within an organizational context (Benbasat and Barki 2007; Riemer and Mantymaki 2012; Venkatesh et al. 2016; Venkatesh et al. 2003).
Further, scholars have attempted to modify these theories by including constructs such as type of technology and demographic information to explain or predict appropriation. Therefore, Goodhue (1995) proposed the notion of task-technology fit, which suggests that appropriation outcomes in terms of performance are more likely to be positive if the selected technology matched the characteristics of the user tasks (Gattiker and Goodhue 2005; Goodhue et al. 1995). Similarly, the Technology Acceptance Model (TAM) was proposed by Davis (1986) and has been influential in IS scholarship to account for factors which motivate or influence acceptance and use of technology by diverse cohorts (Davis 1986; Venkatesh and Davis 2016). Variance class of theories are criticised for overlooking the context of use and over-simplification of the proposed causal relationships that result in adoption or use of technology.

Investigations in this area also contributed the Punctuated Equilibrium Model (PEM), adapted from the ecological psychology domain which revealed the phased nature of technology adaptation and stabilization within the appropriation context (Loch and Huberman 1999; Sabherwal et al. 2001). PEM related studies have been applied to show the changes in technology use due to organizational factors such as social changes or strategic shifts that affect the alignment of an IT artefact with an organization’s goals. Still, PEM studies seem to be focused on analysis at a group level and overlook the appropriation processes of individuals.

Dennis (2001) also proposed the Fit Appropriation Model (FAM) to the context of Group Decision Support Systems (GDSS) in an organization. FAM synthesized findings from prior studies on group decision support systems such as Adaptive Structuration Theory (AST) and task-technology fit to argue that people appropriate technology in different ways; therefore,
how people use a technology is at least as significant as its fit with the task supported by the technology (Dennis et al. 2001; Fuller and Dennis 2009).

Eventually, Davis et al. (2003) proposed the integration of these theories into UTUAT because they only offered fragmented pictures of influences and motivations for technology adoption and use. The original UTUAT still did not account for hedonic adoption and use processes, prompting the development of UTUAT2 by Venkatesh (2016) to account for these appropriation motivations and influences in a non-organizational setting (Venkatesh and Davis 2016; Venkatesh et al. 2003). Nonetheless, most of these variance theories have viewed the process of appropriation through the concept of "use intention" consequently, the process of appropriation is still a black box in these studies.

However, this class of studies have mostly relied on perception-based constructs to measure the use intentions of cohorts. Another limitation of this class of studies lies in the decontextualization, whereby participants in these class of studies are often required to reflect on use outside the context of appropriation. Therefore, critical insights into influences on appropriation have been overlooked or under-reported by these scholars. For instance, Schepers and Wetzels (2007) conducted a meta-analysis to explore the role of subjective norms on the acceptance of an information system using TAM as an example. Their study included contextualized variables such as type of technology, subjective norm or cost in their analysis and highlighted the value of detailed characteristics to enhance the explanatory power of TAM (Benbasat and Barki 2007; Schepers and Wetzels 2007).

Overall, this class of studies have examined use intention instead of the user’s actual interactions with an IT artefact, and as a result, there have been minimal actionable findings to
guide development and understanding of appropriation or dis-appropriation for diverse cohorts. As a result, these studies tend to overlook the context or characteristics of a system which may influence acceptance and use (Benbasat and Barki 2007; Fulk and Gould 2009; Orlikowski et al. 2006).

2.) Process theories in IS studies on appropriation

The second theoretical perspective related to appropriation in IS, the process perspective is based on structuration theory as proposed by Giddens (1984). Structuration theory does not privilege humans or technology during the analysis of emergent social structures, which it posits, are continuously created and recreated in practice (Giddens 1984). Giddens suggests that “the structural properties of social systems are both medium and outcome of the practices they recursively organize”. Structures are the norms, templates, and work process biases that create expectations for how social interactions should take place. Structuration is the process through which actors select, adapt, apply, manipulate and alter available structures. Structures exist because they were enacted by prior action and serve as a guide to shape current interactions, which in turn reinforce, recreate, and redefine structures for subsequent interactions. The “duality of structure” is a dialectic resolved by recognizing that structures guide action while simultaneously being defined by that action. Consequently, each interaction episode is both a singular event with meaning and a building block for an ongoing process (Orlikowski 1992). Figure 2.3 below illustrates the primary modalities of structuration theory.

![Figure 2.4 Structuration theory (Adapted from Giddens 1984)](image)

Gidden’s structuration theory influenced the development of the structuration model of technology by Orlikowski and Robey (1991), which agreed with the propositions of the original
structuration theory in the context of a software organization. Orlikowski and Robey (1991) describe a "duality of technology" that mirrors Giddens’s "duality of structure". The duality of technology suggests that IT is not merely physically constructed by their designer and implementers but are also socially constructed by the interpretive action of users who give meaning to the technology every time they appropriate it. Accordingly, structuration based theories suggest that technologies exert their power of domination when users conform to usage cues delivered with the IT, however, empowered users to create new interpretations that redefine both task and technology structures (Orlikowski and Robey 1991). Both theories imply that the social and power structures in an organization are embodied in the technology. As a result, structuration-based theories do not account for the material influences of technology, but instead take a proxy view of technology as a tool (Jones and Karsten 2008; Orlikowski 2000; Rose and Scheepers 2001).

DeSanctis and Poole (1994) proposed the Adaptive Structuration Theory (AST), which extends Structuration Theory, to suggest that appropriation is an emergent process influenced by the organizational norms, powers structures and several factors including technology features. AST (see Figure 2.5, below) has long been an accepted framework for investigating structures within technological artefacts and work environments. AST provided useful explanations for the interaction or "appropriation moves" applied by a user to bring technology into their practice. As a result, this theory has been useful in explaining variations in appropriation outcomes across contexts through an equal focus on social/organizational influences and technology properties. Further, AST proposed the notion of faithful and unfaithful appropriation to explain how humans may use technology (DeSanctis and Gallupe 1987; Markus and Silver 2008; Poole and DeSanctis 1989).

However, AST has attracted some criticisms for instance: the delineation of technology features into ‘core’ and ‘optional’ is problematic especially given that such an approach could reduce analysis of processes involved in appropriation to a checklist based on features used by cohorts (Markus and Silver 2008). Moreover, scholars have contended the notion of spirit and ‘faithful’ or ‘unfaithful’ appropriation, particularly in the contexts of more flexible technologies such as modern smartphones and other similar technologies which have ambiguity in design. Also, while AST is widely employed to study adaptation and change at the level of groups and organizations, scholars have been reluctant to apply it at the level of individuals (Jones and Karsten 2008). Despite the criticisms of AST, it has helped redirect scholarly focus to the role of the technology in the appropriation process. Still, AST does not account for appropriation
process particularly in the context of flexible, modern technologies with ambiguous application contexts. The notion of technology spirit becomes challenging to evaluate in a non-organizational setting because concepts such as leadership, decision processes or conflict management may not be applicable in a public use context.

Figure 2.5 Adaptive structuration theory (Adapted from DeSantis and Poole 1994)

Similarly, A Model of Technology Appropriation (MTA) was developed by Carroll et al. (2003) to open the black box of the appropriation process among various cohorts and provide a generic scaffold for use in theorizing influences, processes and outcomes of appropriation across diverse contexts. Figure 2.4 below illustrates the initial concepts of MTA, which suggests that appropriation is a three-stage process consisting of encounter; evaluation and stable use or dis-appropriation because of various influences that emerge during technology use. These factors include familiarity, adaptability, ease of learning, psychological ownership, usefulness, ease of use and fashion.

MTA has served as a useful guide to conduct further interpretive study; for instance, Mendoza et al. (2010) examined appropriation in an educational setting, revealing the long-term influences experienced by cohorts during appropriation of two educational tools: endnote and a learning management system. The study confirmed the proposition of Carroll et al. (2007) that there are three main phases of appropriation which are influenced by various factors such as usefulness, ease of use and so on during the process of appropriation by that cohort (Carroll et al. 2007; Mendoza et al. 2010). That study also suggested that access to training resources have a positive influence on appropriation, while unlike the previous study, fashion was not found to influence appropriation.
That study also exposed negative influences on appropriation such as adaptability and learnability of the technology examined (a Learning Management System). The initial version of MTA was developed through a month-long study of youth who were appropriating mobile phones. MTA has since been extended to the various contexts, due to its usefulness as a scaffold for exploring appropriation across various contexts.

The next section discusses scholarly discourse on influences on appropriation identified in related studies.

**2.4 INFLUENCES ON APPROPRIATION FROM RELATED STUDIES**

The majority of IS scholarship has been focused on influences on technology adoption and use focused on individual user’s cognitions and incentives to engage with an IT artefact to carry out their tasks in a particular use context. These studies often pursue the question: “What factors influence the adoption of IS/IT by individuals across various contexts?”. As can be surmised from the above question, these studies generally seek to understand the various factors that are instrumental or detrimental to the process of appropriation, leading to positive or negative outcomes (Jeyaraj and Sabherwal 2008).

According to Fulk and Gould (2009) “Users bring various skills, experiences, and biases. These individual differences will influence both the ways that users perceive technologies and the specific functionalities of a given technology that they actually utilize” (Fulk and Gould 2009). This quote suggests that these characteristics may serve as antecedents which account...
for differences in appropriation processes among similar cohorts. For example, a highly skilled user may efficiently utilize sophisticated technologies which would also affect their perceptions of the “ease of use” in using that technology to accomplish a specific task. Therefore, Fulk and Gould (2009) suggest that researchers pay attention to the characteristics of the users and contexts during studies on appropriation to produce actionable theoretical contributions. Some studies suggest that the user’s intention to continually use an IT artefact may be due to factors such as perceived usefulness; perceived ease of use; familiarity; attitude or; ease of learning (Ajzen 1991; Barki et al. 2007; Benlian 2015; Mendoza et al. 2010). These studies also suggest that characteristics of the user such as level of education, altruistic tendencies or self-efficacy play a role to influence the outcomes of appropriation of various technologies.

However, Beaudry and Pinsonneault (2010) argue that: “Cognitive-based models can hardly capture the full range of emotional reactions of users and account for their relationships to IT use”. Consequently, scholars have also started to examine the influence of emotions on appropriation, particularly in the adaptation class of studies (Beaudry and Pinsonneault 2005, 2010; Christophe et al. 2011; de Guinea and Markus 2009). For instance, Beaudry and Pinsonneault (2010) investigated the coping strategies applied by users in response to the implementation of a new IT in an American bank setting. Their findings suggest that emotions elicited by an IT artefact may influence how and to what extent it is appropriated by its intended users.

Similarly, Ortiz de Guinea and Webster (2013) investigated the effects of emotions on the process of appropriation in a mixed study setting: their sample included 58 workers in organizations for the first study and a student population for the additional confirmatory experiment. Further, their study suggests that these sets of emotions experienced during appropriation vary based on the extent to which users anticipate or are exposed to expected or unusual IT events.

Mendoza et al (2013) also argue for the need to focus on the emotions of a user and their specific sociotechnical needs from a system. Their study examined two cases: appropriation of a Learning Management System (LMS) and appropriation of a Personal Emergency Alarm System (PEAS). Their findings suggest a robust relationship between the emotions reported by their study informants and that their reported perceptions about the examined technologies.

Taken together, these studies contend that aside from cognitions and user characteristics, it is also essential to understand the emotional influences on appropriation. Further, findings from
the aforementioned studies suggest that during appropriation of a technology artefact there are specific emotions that are experienced by users and impact appropriation outcomes. For instance, positive emotions may lead to continued use, while negative emotions may result in disappropriation (Mendoza et al. 2013). However, with the exception of Mendoza (2013) the majority of these studies have focused on exceptional IT incidents such as new system implementation or disruptive IT events. Accordingly, these studies provide a limited snapshot on the influence of emotions on the process of appropriation. In order to adequately evaluate the role and influence of emotions on appropriation, it is necessary to evaluate a standard/complete process of appropriation to gain a better picture of the emotional influences on appropriation.

The aforementioned studies also point to external factors which influence appropriation outcomes and support the notion that technology acts as a trigger for structuration episodes which may involve other factors external to the individual user (DeSanctis and Poole 1994; Orlikowski 2000). For instance, subjective norm; culture, technology features and user training have been found to influence appropriation in an organizational context (Al-Natour and Benbasat 2009; Lamb and Kling 2003; Mendoza et al. 2010). Other contextual factors could include the degree of diffusion of technology, relative advantage or availability of similar products (Carroll et al. 2007; Fulk and Gould 2009; Mendoza et al. 2010; Rogers 1995). Moreover, another critical influence is the task the user aims to accomplish with the IT artefact. Models like FAM and several others have demonstrated that the alignment between the user has intended task-technology serves as an essential consideration to explain use outcomes (Dennis et al. 2001; Fuller and Dennis 2009; Goodhue et al. 1995; Sun et al. 2016).

2.4.1 Influences on SMT appropriation

Several IS scholars have investigated influences on adoption and use of SMTs in enterprise settings. Enterprise Social Media (ESM) is thought to enable competitive advantage within an organization because they make information within an organization visible to relevant members of the work-network (Choudrie and Zamani 2016; Leonardi et al. 2013; Majchrzak et al. 2013). Most studies on ESM in have suggested that factors such as subjective norms, organizational policies, time constraints, organizational pressure or usefulness serve to either positively or negatively influence adoption and use of ESM (Choudrie and Zamani 2016; Stocker et al. 2012). A notable exception is a study by Choudrie and Zamani (2016) which investigated resistance to ESM in an organizational setting and found that appropriation processes of individuals in that context were negatively affected by the organizational policy.
Despite encouragement from senior management in that study, workers were resistant to using the ESN because it was considered a waste of time and hindrance to achieving their assigned work tasks.

Similar to the typical streams of adoption studies numerous influences on appropriation have been reported such as: familiarity, ease of use, usefulness, altruism, demographic factors such as gender/age, hedonic factors such as enjoyment, self-presentation and many others (Ellison et al. 2010; Riemer and Johnston 2012; Subramaniam et al. 2013; Treem et al. 2015). However, studies on voluntary appropriation of social media in the public context differ from historic IS accounts because they have considered other sets of influences that may affect appropriation outcomes.

Moreover, concepts such as perceived usefulness are contextual and in the setting of hedonic technologies like social media, could appear differently from traditional utilitarian conceptions of perceived usefulness. For instance, Rauniar et al. (2014) applied TAM to investigate the adoption of Facebook among student cohorts using a survey methodology. That study found that use of Facebook correlated with student cohorts using a survey methodology. That study found that use of Facebook correlated with student cohorts using a survey methodology. That study found that use of Facebook correlated with utilitarian constructs such as perceived usefulness; perceived trustworthiness, perceived ease of use and that hedonic constructs such as perceived playfulness could determine intention to use and actual use behaviour among their respondents. In contrast, Hsu and Lin (2008) found that perceived usefulness was not significantly related to use intention, rather, hedonic factors such as enjoyment, ease of use and individual factors such as altruism influenced acceptance and continued use of blogging social media tools.

However, both studies did not account for contextual factors that could influence appropriation such as the technology artefact and rely on the use intention construct as a foundation to extrapolate use outcomes or appropriation outcomes.

These scholars argue that because social media appropriation in the public context is personal, voluntary and ubiquitous, there should be a shift towards needs-based theories. Some key theories that have been used in this context include: Uses and gratifications theory (Katz et al. 1973; Ruggiero 2000), social capital theory (Fisher et al. 2016; Wasko and Faraj 2005), motivation theory (Ba and Wang 2013; Lin and Lu 2011) and social support theory (Maier et al. 2015; Shumaker et al. 1984).
2.4.2 Influences on SMT appropriation in healthcare-related studies: Social support related studies

In the healthcare sector, studies on influences to appropriation have used theories from the stress and coping paradigm (Lazarus 1993) especially Social Support Theory (SST) to examine individual incentives to appropriate SMTs. According to Shumaker et al (1984) “Social support is an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient.”. This class of studies suggest that as a result of appraising their chronic illness status, individuals are motivated to adopt SMTs to receive social support which is necessary to cope with chronic disease and achieve positive illness management outcomes. For instance, these studies suggest that through the use of SMTs chronically ill individuals may receive: information support, social support and emotional support (Bender et al. 2013; Coulson 2005; Hajli et al. 2014; Pousti et al. 2014; Wang et al. 2017). Empirical studies in this area seem to lack evidence of material support despite that aspect being a core facet of SST.

For instance, Huh et al (2014) applied social support theory to investigate the use of video blogging technologies (YouTube) for patient education. Their study supports the basic premise of SST indicating that in a video-based SMT, chronically ill individuals engage in a multidirectional social support process that involves the exchange of emotional, social and information resources to enhance illness management activities (Huh et al. 2014). A key finding from that study suggests that video media format allows a deeper engagement with members of the small ad-hoc communities that are forged around video posts made by chronically ill adults living with Human Immunodeficiency Virus (HIV).

Similarly, Wang et al (2017) investigated social support in the context of HIV self-management in the context of an online forum. Their study evaluated a collected dataset from a HIV forum using linguistics analysis to understand to what extent social support could impact self-care behaviours of participants. To that end, their findings support the base premise of SST to suggest that information support has a positive impact on self-care activities of people living with HIV (Wang et al. 2017). According to Wang et al (2017), social support received from online communities serve as a means to improve self-care behaviour for recipients. The study by Pousti et al (2013) takes this idea further and suggests that participation in SMTs for social support help in developing patient empowerment and facilitate the exchange of emotional support. Further, the study highlights barriers regarding distress and emotional discomfort, concerns regarding information quality, lack of computer literacy and legal concerns about
privacy or available regulations. It is important to note that Pousti et al (2013)’s study was conducted on both forums and SMTs like Twitter and Facebook and did not investigate any differences between both contexts. Moreover, that study recruited arthritic, diabetic, depression, asthma and breast cancer patients in addition to some healthcare stakeholders. Therefore, that study did not specifically identify influential factors unique to specific cohorts and overlooked the technological context within which the reported self-management activities were occurring.

Further, studies in this area seem to take an intervention or information behaviour approach that does not shed much light on the mediating role of an SMT that may influence adoption or continued use for illness management. Consequently, there is a limitation in knowledge on what external factors encountered within an SMT might affect the adoption and use of SMTs by chronically ill adults. As a whole, this class of studies (Goh et al. 2016; Hajli et al. 2014; Hatem et al. 2014; Pousti et al. 2014; Wang et al. 2017) contend that the primary influences on appropriation of SMTs and related technologies in this context are a consequence of seeking to exchange emotional, social and information support. Further these studies argue that participation on these technology artefacts result in beneficial outcomes for users. Yet, these studies overlook the potential impacts of the technology artefacts and ignore the processes through which chronically ill adults apply SMTs into their daily illness management practice. Also, findings from these SST studies implicitly suggest that one of the three core concepts that underpin SST are not applicable in the social media environment since they provide no evidence for the effect of material/support.

2.4.3 Related studies on affordances

According to Gibson (1979), the features (or feature-list) of an object exist/s apart from the people who use them, but those features are infused with meaning “relative to the posture and behaviour of the animal being considered” (pp. 127–128). Researchers in the IS field have used the notion of affordances to understand the action possibilities available to users of an IT artefact (Goh et al. 2011; Majchrzak et al. 2013; Majchrzak and Markus 2012; Treem and Leonardi 2012). More recent studies stress the importance of the social environment in influencing users’ perception and realization of affordances and scholars suggest that users may perceive the possibilities of actions available in a technology design as either constraining or enabling according to their social norms and beliefs (Bernardi 2016; Vaast et al. 2017). Table 2.2 below outlines some examples of affordances which have been conceptualized by related studies.
Table 2.2 Affordances identified in some related studies

<table>
<thead>
<tr>
<th>Affordance</th>
<th>Definition</th>
<th>Author(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>Users can choose and control what they want to disclose about their identity and their medical condition. Individuals can control when and how they communicate details known by other users on the SMT about themselves.</td>
<td>(Kietzmann et al. 2011; Merolli et al. 2013a, 2015; Schultze 2011)</td>
</tr>
<tr>
<td>Flexibility</td>
<td>Possibility of communication and interaction anytime, anywhere. SMTs enable asynchronous communication anytime, anywhere between members of a network without geographic restriction.</td>
<td>(Merolli et al. 2013a, 2015)</td>
</tr>
<tr>
<td>Structure/Visibility</td>
<td>The ability of SMTs to guide participants to relevant information or support resources. Our notion of visibility is tied to the amount of effort people must expend to locate information.</td>
<td>(Merolli et al. 2013a, 2015)</td>
</tr>
<tr>
<td>Narration</td>
<td>Narration refers to the ability of SMTs to record and share experiences of illness. Through narration, individuals can learn from each other and achieve emotional catharsis.</td>
<td>(Broderick et al. 2005; Merolli et al. 2013a, 2015)</td>
</tr>
<tr>
<td>Adaptation</td>
<td>Ability to change use patterns and access information based on the evolving needs of the chronic illness.</td>
<td>(Merolli et al. 2015)</td>
</tr>
<tr>
<td>Metavoicing</td>
<td>Ability to react to activities and presence of other users online. Fosters an ongoing virtual conversation and amplifies the audience of an SMT post.</td>
<td>(Majchrzak et al. 2013)</td>
</tr>
<tr>
<td>Triggered Attending</td>
<td>Refers to the SMT support for notifying users of content relevant to their interests through notifications and automated alerts.</td>
<td>(Majchrzak et al. 2013)</td>
</tr>
<tr>
<td>Network-Informed Associating/Association</td>
<td>The ability for users of an SMT to selectively engage in conversations based on relationship ties either to other users in the network or based on content. It also enables formulation and articulation of new relationship ties between members of the SMT supported network.</td>
<td>(Majchrzak et al. 2013; Treem and Leonardi 2012)</td>
</tr>
<tr>
<td>Generative Role-Taking</td>
<td>Refers to SMT support for its users to take on roles within the network to foster community engagement.</td>
<td></td>
</tr>
<tr>
<td>Persistence</td>
<td>Communication is persistent if it remains accessible in the same form as the original display after the actor has finished his or her presentation (Bregman).</td>
<td>(Treem and Leonardi 2012)</td>
</tr>
<tr>
<td>Editability</td>
<td>Editability refers to the fact the individuals can spend a good deal of time and effort crafting and recrafting a communicative act before it is viewed by others. Editability can also refer to the ability of an individual to modify or revise content they have already communicated</td>
<td>(Treem and Leonardi 2012)</td>
</tr>
</tbody>
</table>
More recently, scholars have started to examine the affordances of SMTs for chronically ill cohorts. For instance, Merolli et al. (2013; 2015) proposed a set of therapeutic affordances experienced by chronically ill cohorts by applying SMTs to their illness management practices. Among the identified affordances were: narration, self-presentation, identity, flexibility, structure and adaptation (Merolli et al. 2013a, 2015). Similarly, Pousti et al. (2013) and Bernardi (2016) examined SMT in the context of chronic illness, and collectively found a set of affordances that may influence outcomes and serve to motivate continued engagement with these SMT communities.

With the exception of the study by Pousti et al. (2013) the examined studies on SMT affordances have neglected potential negative affordances, leading to an imbalanced notion that SMT only offers positive, enabling affordances to its users. The study by Pousti applied a sociomaterial perspective that identified four main constraints from SMT appropriation in the chronic illness context which include: emotional discomfort, legal implications, low self-efficacy, poor information quality and social concerns.

Yet, that work did not delineate which actors (chronically ill individuals, healthcare providers or the carers in the study) in the SMT context were constrained by the disruptive affordances reported by the study. This distinction is important because affordances are specific to the type of actor who encounters them (Recall the definition of affordances proposed in Section.2.4.1). Some scholars suggest that affordances should be viewed through a socio-technical lens (Bernardi 2016; Majchrzak et al. 2013; Merolli et al. 2013a). A socio-technical view of affordances proposes that they are only partially determined by the features of a technology and emerge from the user’s task-oriented interactions with an IT artefact (Bernardi 2016). Accordingly, in health-related studies, affordances are conceptualized as potential outcomes from adoption and use of an SMT to manage chronic illness.

2.4.4 Identified limitations

1. Taken together, the aforementioned studies have overlooked the potential influence of the technology artefact on appropriation outcomes. In particular, studies on ESM or SMT did not account for the technology features and gave a limited account on other contextual influences on appropriation mainly because this area has been dominated by quantitative studies resulting in weak explanation of context (McKenna et al. 2017; Urquhart and Vaast 2012).
2. There is room to further unpack social influences in the public context regarding structures/context that may affect SMT appropriation as these studies have not acknowledged the unique characteristics that may be encountered from social media (Burton-Jones and Gallivan, Micheal 2007; Christophe et al. 2011; Fulk and Gould 2009; Griffith 1999; Griffith and Northcraft 1994; Orlikowski et al. 2006).

3. The examined studies indicate fragmentation in theory on individual incentives to adopt or use an SMT. The hedonic and healthcare studies focus on needs-based influences, while the IS studies focus on utilitarian, task-related needs. The context of chronic illness management could benefit from a holistic evaluation of hedonic and illness-related factors because illness management is a daily ongoing task.

4. Studies on affordances have neglected potential negative affordances, leading to an imbalanced notion that SMT only offers positive, enabling affordances to its users. The one study by Pousti et al (2014) did not delineate the specific constraints that were experienced by chronically ill adults due to a mixed cohort. Accordingly, there is room for further work that examines the enabling and disruptive affordances provided by SMTs to specific groups of users that impacts accomplishment of their specific tasks.

2.5 UNPACKING THE PROCESSES AND AFFORDANCES OF TECHNOLOGY APPROPRIATION IN RELATED STUDIES

Initially, scholars considered appropriation as a predictable outcome, which could be statistically measured and anticipated based on specific dependent and independent constructs and so research focused on influences on the adoption or use processes. Over time, scholars have suggested that appropriation is an emergent process influenced by the user, their social environment and their need/goal (Beaudry and Pinsonneault 2010; Mendoza et al. 2010). Further, within the context of appropriation scholars have indicated that users may interact with the system in expected (faithful appropriation) or unexpected ways (unfaithful appropriation), and; users may change roles- creating emergent roles while interacting with the IT artefact (Dourish 2003; Leonardi et al. 2016; Markus and Silver 2008; Ortiz de Guinea and Webster 2013). Still, the notion of faithful or unfaithfulness of appropriation loses explanatory power in a public context. Technologies disseminated for public use such as SMTs are designed to be flexible in order to induce diffusion and adoption by members of the general public for their needs or goals.
Past studies suggest that the appropriation process consists of a sequence of steps which could lead to appropriation or dis-appropriation depending on various contextual influences (Jasperson et al. 2005; Jeyaraj and Sabherwal 2008; Mendoza et al. 2010; Riemer and Johnston 2012). Under the sequential perspective on the process of appropriation, Tyre and Orlikowski (1994) argued that technology use stabilizes after a period of initial adaptation following the implementation of new technology and the window of opportunity may then close (Tyre and Orlikowski 1991). In contrast, Mendoza et al (2010) examined appropriation and suggested that it is sequential, occurring in three main levels:

- Users are introduced to the technology, and they are faced with the decision of whether to adopt the technology or not during these initial encounters with the ICT,
- A period of evaluation and experimentation with the new technology where the user may adapt to the ICT or attempt to adapt the ICT to suit their needs,
- Stabilized or persistent use of technology (Mendoza et al. 2010), and

According to Mendoza et al (2010) appropriation process may also result in re-entry by a user; therefore, in their study, appropriation is a dynamic process.

### 2.5.1 Unpacking the process of SMT appropriation

Although SMTs have attracted growing attention by IS scholars, few studies have investigated the processes or usage patterns involved in appropriation of an SMT. A few notable exceptions exist which include the studies by Reimer and Johnston (2012) and Choudrie et al. (2016). Riemer and Johnston (2012) examined the appropriation processes of Yammer, an enterprise-wide social media (ESM) tool. According to, Riemer and Johnston (2012), appropriation of ESM is phased, bottom-up and involved collective sensemaking by users in that context (Riemer and Johnston 2012) (Riemer et al. 2012; Riemer and Johnston 2012). That study suggested four different, interconnected phases of appropriation, including ‘encounter’, ‘place-making, ‘performing meaning’, and finally, ‘performing the practice’ of an enterprise SMT.

Encounter phase suggests that users may inspect the ESM to determine how best it can be applied to their existing work practices. Placemaking phase refers to increased use and evaluation of the IT artefact against other existing options in the enterprise. Performing meaning through yamming practice refers to the everyday use of an ESM, where the technology
fades to the background of sensemaking practices by cohorts in the enterprise. Finally, performing the practice refers to stabilization of the ESM, where it attains a role in the daily work practices of an organization.

Still, their study did not solicit primary data from the users, without interaction with the users of the system, some aspects involved in appropriation which may not be evident from analysis of the Yammer text corpus were overlooked. For instance, there is no mention of ‘lurking’ or other less proactive appropriation activities which have been suggested by other studies (Han et al. 2014).

In contrast, Choudrie and Zamani (2016) investigated both the influences and processes involved in the appropriation of an information system. Their study found that there were bidirectional tensions that influenced the successful or unsuccessful appropriation of social media in an ESN context which resulted in user resistance or construction of workarounds. Choudrie and Zamani’s (2016) study revealed there are two different categories of reasons for working around the two ESNs or ignoring them altogether, that is: 1) bottom-up pressures emerging from the daily work constraints, and 2) the various pressures from the organizational environment.

Taken together, these studies present a clearer picture of the dynamic and contextual nature of appropriation in an organizational setting. Nonetheless, the studies above outlined the process of appropriation within an enterprise setting where there are explicit mandates (e.g., Choudrie and Zamani (2016)) and organizational pressures to use SMTs for socialization, work practices and knowledge sharing tasks. Conversely, appropriation is voluntary in the public context and SMTs may constantly evolve because public SMTs are in a constant state of development.

### 2.5.2 Appropriation as a sociomaterial process

According to Orlikowski (2009), technologies and human action have a mutually shaping effect on each other resulting in an inseparable practice called “entanglement”. The notion of entanglement yields considerable insight into the relational aspects of appropriation, but there are several points of ambiguity. First, the notion of inseparability during the appropriation process leads to considerable difficulty in applying this perspective to empirical research. Secondly, an entanglement perspective overlooks the separate identities and characteristics of human actors and technological objects in practice (agency of the social and material).
Similarly, Treem and Leonardi (2012) proposed the concept of ‘imbrication’ (still within the umbrella of sociomaterial theory) which considers the technology and human elements separable because they are interwoven in practice, not entangled (see Figure 2.2, below). The imbrication perspective allows identification of snapshots of adjustment processes in the appropriation context called “imbrications”. While the imbrications perspective acknowledges the separability of technology and human agents, yet it still takes a high-level view of the capabilities of these technologies and does not consider the goal-oriented nature of appropriation nor the processes involved in appropriation. Further, the majority of studies conducted under sociomaterial lenses suffer from two issues: a highly localized focus on snapshots of user interactions with a technology artefact and highly abstracted accounts of the process of appropriation (Gaskin et al. 2014). As a result, sociomaterial studies on appropriation lack the ability to offer practical insights that may inform the design of SMTs for specific use contexts and lack of generalizability to inform theory in other use contexts.

![Organizational Structure](image)

**Note:** In Panels A and B, the activity occurring within the gray square represents actions constitutive of broader organizational structure. In Panel B, horizontal arrows signify flows through time. Diagonal arrows signify actions’ slow but cumulative entanglement with structure (and vice-versa) through the through the imbrication of material and social agencies. The dashed line represents imbrications that occurred before focal actor began using technology.

![Figure 2.7 Sociomaterial practice, imbrications perspective (Adapted from Treem and Leonardi 2012)](image)

### 2.5.1 Process of appropriation in related healthcare studies

According to Agarwal et al. (2010), it is imperative to understand who the users of SMTs in the healthcare context are and how they use internet technologies such as SMTs to maintain health and well-being. Yet, it seems that process of use has been overlooked by scholars. For instance, numerous scholars have focused on influences and outcomes of SMT use by chronically ill adults using theories like SST and affordance theory (Bernardi 2016; Goh et al. 2016; Merolli et al. 2015; Pousti et al. 2014; Wang et al. 2017). Aptly, Chung (2014) argues that despite the extensive literature in the domain, little is known about how individuals use online social groups. Chung (2014) states that usage patterns impact the outcomes obtained
from using the technology. Also, changes in the features and functionalities of systems impact the benefits obtained by using social media (Chung 2014). Adults with chronic illness tend to try out a variety of tools in the course of their illness management journey (Bender et al. 2013). Therefore, an examination of the SMTs and other external influences than the needs-based theories could yield new insights into the usage patterns and appropriation behaviour of these users (Agarwal et al. 2010; Chung 2014).

2.5.2 Identified limitations

1. The studies on the processes of appropriation assume that technology remains static and does not take the evolutionary nature of newer technologies like SMTs into account, particularly in the public context.

2. The sociomaterial perspectives (imbrications or entanglements perspectives) has been useful to resolve the question of technological agency in appropriation, yet the sociomaterial class of studies proffer a high-level view and do not offer much insights into the sequences or episodes (DeSanctis and Poole 1994) involved in appropriation. These studies on SMT appropriation have overlooked the unique interactions between a user and an SMT. The extant studies that have investigated the process of appropriation of ESM have taken a high-level view because they did not solicit primary data from users (Riemer and Johnston 2012).

3. While affordances may act to enable or disrupt continued use, they are distinct from the process of appropriation or the factors which influence appropriation. Instead, by its definition, affordances are a consequence of the technology environment and the behaviour/posture of the user on an SMT. Studies which have applied an affordance lens in the chronic illness context have overlooked the influences and processes which result in those affordances.

2.6 SUMMARY OF LIMITATIONS AND PRACTICE LENS

In summary, findings from the literature review highlights several gaps in the appropriation of SMTs in the context of chronic illness management. The following gaps guide the focus of this study:

- There is a fragmentation in reported influences on SMT appropriation; chronic illness studies tend to overlook the technology features and other factors such as ease
of use for these SMTs. Particularly in terms of the cognitions, emotions and needs of individuals with a chronic illness that acts as an incentive to adopt and use SMTs.

- There is room for a more in-depth investigation into the influences of technology on appropriation outcomes, particularly in the public context. In the chronic illness context, the technology artefact is typically absent in this class of studies. Therefore, there has been a limited account for why these reported influences on appropriation occur.

- There seems to be a paucity of studies into the processes of appropriation on social media because most studies use variance theories and so do not unpack the processes. Conversely, other scholars have applied a sociomaterial lens to examine appropriation processes, leading to highly localized descriptions that do not lend itself to a deeper understanding of the activities involved in appropriation of technologies like social media.

- These studies seem to report affordances without acknowledgement of how they are encountered due to some studies conflating affordances with the process of appropriation.

### 2.6.1 Practice lens for this study

Previous studies suggest that IS studies may apply existing theory as a scaffold to take account of previous knowledge and extend that practice lens through findings (Majchrzak et al. 2000; Orlikowski 2000; Walsham 1995). For instance, Orlikowski (2000) applied structuration theory as a practice lens to guide interpretation of her study into appropriation of notes technology in an enterprise setting. Similarly, this present study applies a practice lens of three theories to act as a scaffold and guide interpretation of findings. The applied practice lens in this work combines three theories: (1) Model of Technology Appropriation (MTA) (Refer to Section 2.3.3), (2) Social Support Theory (SST) (Refer to Section 2.4.2), and (3) affordance theory (Refer to Section 2.4.3), into a practice lens to guide analysis of this study. The proposed practice lens is presented in three aspects labelled as A, B and C illustrated in Figure 2.8 below:
Figure 2.8 Practice lens for the study, extending MTA with SST and Affordance theory
• **Model of technology appropriation (A):** The first aspect is based on MTA which is a process model that describes processes and factors identified as negative and positive influences on appropriation (Carroll et al. 2007; Mendoza et al. 2010). MTA suggests that factors such as technology features, perceived usefulness, adaptability, ease of learning, access to training, relative advantage, purchase cost, fashion/style, familiarity and subjective norms may serve to influence appropriation outcomes (Carroll et al. 2007; Mendoza et al. 2010). Moreover, MTA outlines some negative influences on appropriations such as lack of adaptability, lack of ease of learning and lack of integration. Further, MTA also outlines three stages of appropriation: initial encounter, evaluation and stable use. The initial version of MTA suggests that at each phase a set of influences may encourage or discourage appropriation until use is stabilized in phase 3 (Carroll et al. 2007; Carroll et al. 2002). However, the extended MTA argued that stabilization in use of a technology may only be temporary and further appropriation could occur based on evolved influences and the user’s expectations from technology (Mendoza et al. 2010). In this study, MTA served to guide insights into the influences and processes of appropriation of SMTs, yet MTA did not account for the emotional nature of chronic illness nor the affordances that may be encountered during appropriation of SMTs.

• **Social Support theory (B):** Accordingly, the second theory applied in our practice lens is based on social support theory which suggests that social connections may be leveraged to alleviate the effects of stress and improve illness management outcomes for chronically ill cohorts (Barrera 1986; Lazarus 1993; Pousti et al. 2014; Shumaker et al. 1984; Wang et al. 2017). SST is commonly used in healthcare-related studies as a lens to understand individual motivations for adoption and use of online communities. Further, SST suggests that chronically ill adults (depending on their level of self-efficacy) are incentivized to participate in these SMTs in order to exchange: emotional, information, social, material and esteem support which aids their illness management practices (Bandura 1998; Barrera 1986; Huh et al. 2016; Lazarus 1993). In this study, SST was applied to derive richer insights concerning influences on appropriation specific to chronically ill individuals and compensate for emotional factors which could influence appropriation in this study.
• **Affordance theory (C):** Finally, the third theory in the practice lens was informed by the theory of affordances which suggest that an IT artefact offers certain action possibilities depending on the user and their goals (Gibson 1986; Majchrzak et al. 2013; Treem and Leonardi 2012). Affordance theory was applied to guide interpretation of the affordances which enable or disrupt appropriation of these examined SMTs for chronic illness management. Accordingly, the practice lens suggests that affordances specific to illness management are experienced by these individuals during the process of appropriation (Bernardi 2016; Gibson 1986; Leonardi 2011; Majchrzak et al. 2013; Majchrzak and Markus 2012; Merolli et al. 2013a). Related studies on social media had suggested that SMTs afford narrativity, structure, flexibility, triggered attendance and metavoicing to its users.

2.7 SUMMARY

This chapter presented the results of literature review of multiple information systems domains including technology appropriation, social media and healthcare with a focus on chronic illness following the methodology proposed by Webster and Watson (2002) (see Section 2.2). The results that emerged from the synthesis of the literature were presented to develop rich insights that serve as the theoretical background for the study. Additionally, this chapter identified gaps related to influences, processes and affordances that may be experienced by chronically ill individuals during appropriation of SMTs for illness management. Finally, the chapter concluded with a practice lens which frames the analysis of findings from this thesis. The next chapter provides a detailed description of the research design and methodology used in this study.
Chapter 3: Research design

INTRODUCTION

The previous Chapter 2 reviewed related studies and highlighted the limitations in current knowledge that motivate this study. Based on those limitations (see Chapter 2, Section 2.6), this present Chapter 3 provides the research procedure designed to examine social media appropriation by chronically ill adults. Hence, Chapter 3 proceeds as follows: Section 3.1 reiterates the research aim of this investigation and Section 3.2 discusses the main research perspectives used in previous IS scholarship to guide the conduct and interpretation of research in information systems (IS). Next, Section 3.3 discusses the three research strategies typically applied to IS scholarship. Subsequently, Section 3.4 highlights the research design applied to this study and covers issues regarding the application of a multiple case study with mixed methods to drive further understanding of social media appropriation across four tools, by chronically ill adults.

Further, Section 3.4 also provides the unit of analysis, participant details and case boundaries for this study. Next, the data collection and analysis tools that have been applied to the study are outlined in Section 3.5. Following this, Section 3.6 outlines the ethical considerations and protocols that act as a boundary for the conduct of this study. Finally, this chapter concludes with the limitations and potential issues that may arise during this research work (Section 3.7).

3.1 AIM OF THE STUDY

Recall that this study aims to gain a deeper understanding of how adults with chronic illnesses engage with and appropriate social media tools to better understand and manage their illness. Based on the literature review conducted in Chapter 2, three assumptions are implicit in the aim of this research which influences the conduct of the study: 1) there are several influences on appropriation outcomes; 2) appropriation is a goal-oriented process and; 3) a variety of affordances are experienced during the process of appropriation because they are goal oriented and relative to the actor in an environment (Leonardi et al. 2016; Mendoza et al. 2010; Richter and Riemer 2013; Schmitz et al. 2016; Wiredu 2007).
The following Section outlines three dominant research perspectives in Information Systems (IS) research

3.2 RESEARCH PERSPECTIVES IN INFORMATION SYSTEMS (IS) RESEARCH

Within the IS domain, there are three primary research perspectives which are applied to conduct empirical investigations: positivist, interpretivist and critical realist (Cavaye 1996; Galliers and Land 1987; Gregor 2006b; Lee 1989; Myers 1998; Walsham 1995; Walsham 2006). The following section gives a brief overview of these three perspectives, including a brief discussion on their benefits and limitations.

3.2.1 The positivist research perspective

A positivist perspective assumes that an objective reality exists which can be examined separately from subjective social influences within an environment. Positivist research also holds that laws that govern social realities are stable and measurable through an examination of the social actors’ responses using various instruments such as questionnaires or experiments (Cecez-Kecmanovic 2011a). Myers and Klein (1999) state that positivist studies exhibit the presence of formal propositions, quantifiable variables, hypothesis testing and drawing inferences from a representative sample which are then generalized to a larger population (Myers and Klein 1999). Positivist researchers typically select methods to reduce the influence of the personal biases of the investigator during research to ensure unprejudiced conduct of research (Becker and Niehaves 2007; Neuman 2006, 2012). Because objectivity is so valued in positivist research, several control measures are applied and may take the form of instrument validations before undertaking the study such as: examining scale reliability; examining construct validity and conducting pre-tests or pilot testing before undertaking the study (Boudreau et al. 2001; Creswell 2009).

A vast majority of IS scholarship have applied a positivist perspective which led to some seminal theories such as: TRA (Ajzen and Madden 1986), TAM (Davis 1989), TPB (Ajzen and Madden 1986), UTAUT (Venkatesh et al. 2003) and others which have led to important discoveries about the nature of influences on acceptance, adoption or use of technology across various contexts.
Still, positivist studies are limited because they are unable to adequately account for complicated, messy, subjective nature of socially constructed issues or processes (Cecez-Kecmanovic 2011a; Cecez-Kecmanovic and Kennan 2013).

### 3.2.2 The interpretivist research perspective

Interpretivist research contends that reality is subjective and a consequence of mental/social constructions of actors in various contexts/environments. Interpretivism is derived from the hermeneutics field in social science/behavioural science (Myers 1998; Walshaw 1995). A key goal for interpretivist researchers is to allow meaning to emerge from interpretation as they immerse themselves in a research setting so, they do not enter a study context with pre-defined constructs. Extant theory may be applied as a practice lens or scaffold to guide the interpretation of phenomena (Walshaw 1995). Within IS scholarship, interpretivism is said to be: “aimed at producing an understanding of the context of information system and the process whereby the IS influences and is influenced by its context” (Myers and Klein 1999).

Accordingly, interpretivist study is valued because it provides rich insights to the lived experiences of research subjects by attempting to undertake the construction of reality emically, contextual meanings and interactions encountered by research subjects in a given context (Creswell 2009; Myers and Klein 1999; Neuman 2012). In contrast to the positivist perspective, interpretivism views knowledge as the result of social constructions between the researcher and the research subjects and so relies heavily on the explanatory power of the researcher to lend credence to their account of the actions and processes in a given study context. Therefore, the quality assessment for a good interpretive study relies on its authenticity, plausibility and criticality (Butler 1998; Cecez-Kecmanovic 2011a; Schwandt 1994).

However, this leads to the shortcoming of interpretivism, whereby the validation of the conducted research in terms of rigour and correctness relies on the logically consistent, subjective and thorough account of the researcher (Cecez-Kecmanovic 2011a).

### 3.2.3 The critical realist research perspective

The critical realist (CR) perspective agrees with the positivist perspective that there is a world independent of our knowledge that exerts impact on human experiences. However, CR challenges this objective perspective because it also
believes that the experience of this world is mediated by the perceptions of an actor within an environment (Mingers et al. 2013). Unlike the positivist or interpretivist approaches, CR is driven by explicit/specific ethical and value positions and more importantly, aims to challenge and change established social institutions and conditions (typically enabled and supported by IS) (Mingers et al. 2013; Wynn and Williams 2012). Consequently, critical research differs from positivism or interpretivism, both of which “are content to predict or explain the status quo” (Orlikowski et al. 1991).

Because CR is inherently emancipatory, in IS scholarship it is valued as a catalyst for change since it: “aims to reveal and transform oppressive forms of control, which prevent the realization of humane, just and free organizations and society” (Cecez-Kecmanovic 2011a, 2011b). CR research assumes that evaluated events and experiences occur within an objective structure, mediated by contextual factors. The majority of CR studies aim to explain how structures and events within a context are generated through mechanisms without any intention towards replicability or prediction (Mingers et al. 2013). Similar to interpretive assessment criteria, validity in CR involves the use of quality assessment principles such as authenticity, plausibility, criticality and empirical corroboration of the reported study (Cecez-Kecmanovic 2011a; Mingers 2004; Williams and Karahanna 2013; Wynn and Williams 2012).

The CR perspective is limited in the following ways: despite the stance on objective reality, the process of interpretation tends to yield multiple, untestable explanations further compounded by its rejection of typical traditional empirical testing or verification mechanisms (Mingers 2001; Mingers and Willcocks 2004).

The following section briefly discusses the dominant research strategies in information systems scholarship.

3.3 OVERVIEW OF RESEARCH STRATEGIES IN INFORMATION SYSTEMS

Three main research strategies applied to IS scholarship: quantitative, qualitative and mixed methods strategies, explained in the next three sections.

3.3.1 Quantitative research strategy

A quantitative strategy is typically associated with a positivist stance and consists of methods such as experiments or surveys, which are designed to measure an
objective reality to deductively explore causality within a research setting (Creswell 2009). Concepts of interest are decomposed into constructs/variables which are then developed into an instrument consisting of independent variables which are thought to apply a causal effect on dependent variables within a study setting (Creswell 2009; Guba and Lincoln 1994; Lincoln and Guba 1985). Quantitative studies are typically regarded as having a high degree of accuracy and replicability, due to the logical, objective design of related constructs, instrument development, and sampling strategies (Collins et al. 2006; Onwuegbuzie and Leech 2007). Quantitative methods have the following strengths: (1) operationalization of key constructs; (2) ability to explore casual associations between variables; (3) support for model specification and hypothesis testing; 4) replicability and; 5) generalizability (Creswell 2009).

Still, purely quantitative studies tend to overlook contextual influences on the results of a study, and as a result, the trade-off for generalizability leads to de-contextualization of the specific factors that may shed further light on the research results (Castro et al. 2010; Gregor 2006a).

### 3.3.2 Qualitative research strategy

In contrast, a qualitative strategy involves the use of methods such as interviews, observations, case studies, ethnography and other similar methods with the aim to infer meaning from a phenomenon through rich understandings derived from the context of a research setting (Ceecez-Kecmanovic 2011a; Denzin 2012; Hsieh and Shannon 2005; Maxwell et al. 2005; Myers 1997; Silverman 2006). Qualitative studies are concerned with the positions of social actors in situ. Therefore, attention is given to deep holistic analysis of phenomena in their natural environment (Cavaye 1996; Darke et al. 1998; Walsham 1995; Walsham 1995; Walsham 2006).

Analyses within the qualitative paradigm typically take on either inductive or deductive approaches to emically derive a rich understanding of the phenomenon in context. Unlike quantitative research, qualitative studies aim to yield: (1) rich narrative accounts of personal human experiences; (2) in-depth analysis of complex social systems (Creswell 2009). Additionally, these studies are often conducted in participants’ social settings, allowing building from specifics to general themes, and then the researcher applies their interpretation of the collected data.
Nonetheless, qualitative researchers often have difficulty in triangulating evidence from multiple sources and difficulties in capturing associations that occur within and between cases or observations (Bazeley 2009; Castro et al. 2010). Also, as a consequence of striving for rich description, qualitative studies tend to make use of small samples, sometimes resulting in non-generalizable findings (Bazeley 2009; Castro et al. 2010; Yin 2013).

3.3.3 Mixed methods strategy in information systems research

A mixed methods strategy involves the use of both quantitative and qualitative data for combined integration and analysis. Mixed methods studies aim to provide a richer understanding through leveraging the strengths of quantitative and qualitative methods within a research context (Creswell et al. 2003; O’Halloran et al. 2016). For example, a mixed methods study could involve interviews with key informants and a survey after which data from both data collection methods are analysed separately and integrated during the presentation of the findings. The goal of mixing methods is to leverage the strengths of both quantitative and qualitative methods while overcoming limitations of either method (Creswell et al. 2007; Onwuegbuzie and Collins 2007; Venkatesh et al. 2013, 2016). Through this integration, a mixed methods study can provide a complete understanding of a research problem through the use of quantitative and qualitative elements within the same of different study contexts (Creswell and Clark 2007; Venkatesh et al. 2013).

Despite the anticipated benefits of mixing methods, data integration in mixed methods research is challenging because there are several contradictory views on when integration should occur: at data collection; during analysis; or during interpretation (Venkatesh, Brown, et al. 2016; Venkatesh and Brown 2013).

3.4 Research design selected for this study

According to Yin (2013), there are three characteristics that should be considered when choosing a research design for a study: (1) The type of research question posed, (2) the extent of control a researcher has over an actual behavioural event and (3) the degree of focus on contemporary events, as opposed to entirely historical events. With these design criteria in mind, this study took an interpretivist perspective to obtain rich insights into the context of social media appropriation by chronically ill adults. Given that the study is driven by ‘how’ and ‘why’ type of questions, it was essential to apply
a case study methodology to obtain a rich understanding of social media appropriation within the context of chronic illness management. Moreover, an interpretive perspective allows for capturing the experiences of the research subjects and then interpreting these to show the processes and influences involved in the appropriation of social media by chronically ill adults.

Furthermore, this study used a multiple case study approach to allow for the examination of social media appropriation by chronically ill cohorts within its context - social media tools (Yin 2013). Given that a case study approach is recommended to examine contemporary phenomena and when an issue is not well understood, this approach suits the aim of the study.

Numerous scholars have argued that social media research in IS could benefit from the application of case studies and similar methods to drive theoretical development about processes and influences facilitated by these tools (McKenna et al. 2017; Urquhart and Vaast 2012). More importantly, the use of a multiple case study will aid in strengthening theoretical development by highlighting the conditions and interrelationships between concepts that are necessary for different appropriation outcomes among these chronically ill cohorts (Miles et al. 2014). Moreover, through a multiple case study approach, this study can explore unique themes within each case and generalize themes which are found across each research site (Eisenhardt 1989; Miles et al. 2014; Walsham 1995; Yin 2013).

3.4.1 Mixed methods research strategy in this study

Next, to derive a complete understanding of social media appropriation and leverage the types of data available through social media, this study leveraged a mixed methods research strategy (Creswell and Clark 2007; McKenna et al. 2017). This involved the collection of social media data using the tool application programming interface (API) parallel to conducting observations and semi-structured interviews with key informants recruited from these sites. A key challenge when conducting studies with social media lies in the voluminous, noisy and hard-to-interprettex- corpus generated by the API, therefore the use of quantitative data analytics methods allows for sensemaking of this data through data reduction and theoretical grounding through application of the practice lens of the study (Abbasi et al. 2016; Deboratoli et al. 2016; McKenna et al. 2017). Moreover, the mixed methods strategy allows the
researcher to corroborate the quantitative findings with the qualitative findings, which is a form of methodological triangulation (Bryman 2009; Denzin 2012).

This qualitative and quantitative data collected from these social media sites were integrated through weaving the narratives of the thematic findings from each case to achieve convergence and provide a complete understanding of social media appropriation by chronically ill adults (Bryman 2009; Fielding 2012; Moseholm and Fetters 2017; Yin 2006). This design, therefore, made use of existing social media data derived from the application programming interface (API) of each social media tool. Hence, this thesis’s design can be described as a multiple case study with convergent mixed methods design (Abbasi et al. 2016; Collins et al. 2006, 2007; Creswell 2009; Creswell and Plano Clark 2011; Fetters et al. 2013; O’Halloran et al. 2016). In summary, Figure 3.1 below outlines the research design applied to this study.

Figure 3.1 Research design for the study and corresponding thesis chapters
First, as demonstrated in Figure 3.1, the review of related literature helped to scope this research context and guided our selection of the practice lens for this research, which extends MTA with SST and theory of affordances.

Second, as illustrated above, all four case studies were conducted in parallel, with data collection for all 4 cases commencing from June 2016 until September 2017. As the notation ‘QUAL + quan’ in Figure 3.1 illustrates, each case study was designed for the convergence of the data analytic text corpus and the qualitative data (interview and observation). Findings were integrated for each case through narratives weaving around the key themes identified through interpretive analysis of the case study interview data (Creswell et al. 2011; Jick 1979; Venkatesh, Brown, et al. 2016).

Next, a cross-case synthesis was carried out to evaluate similar or unique themes across the four cases and to better understand the boundaries of the developing theory on social media appropriation in the context of chronic illness (Eisenhardt 1989; Eisenhardt and Graeber 2007; Miles et al. 2014; Walsham 2006). The following section discusses the research context and sampling strategies that were applied to guide this study.

3.5 RESEARCH CONTEXT AND SAMPLING

According to Eisenhardt and Graeber (2007), the main aim of sampling for a multiple case study is to develop a theory based on the research aims of the proposed study. This process is known as theoretical sampling and involves deciding on which analytic grounds the sample should be chosen (Charmaz 2006, 2008; Eisenhardt and Graebner 2007). Previous scholars have outlined strategies for theoretical sampling that involve maximizing or minimizing the differences either between groups or between concepts in the data (Glaser and Strauss 1967; Urquhart and Vaast 2012). In accordance with recommendations from Eisenhardt (1989), four different SMTs were selected to enhance the generalizability of findings from the study.

This study applied the framework provided by Ngai et al. (2015) based on Media Richness Theory (MRT), which classified social media tools based on their unique features. Based on this, four social media tools - Facebook, Instagram, YouTube and Reddit were selected as the specific cases for examination in this study (Ngai et al. 2015; Ngai et al. 2015). Reddit is a text-based SMT, similar in structure to an online bulletin board; YouTube is primarily a video sharing SMT, Instagram is chiefly an
image sharing SMT and Facebook a social media site that contains a hybrid of features that include text, images and videos. It is necessary to note that these selected SMTs may also have other features and capabilities; for example, Instagram also allows sharing of short videos called “stories” which are available for 24 hours. Moreover, throughout the study, these SMT underwent several updates which expanded their feature-set to include other functionality; for instance, YouTube restricted the messaging feature and added image sharing functionality. Also, these four social media tools are among the most used social media tools globally (Burzler 2018; Fadel 2012; Sareah 2015).

Given the differences/heterogeneity of the included SMTs, the research focused on one chronic illness - fibromyalgia. Fibromyalgia is a long-term chronic condition which presents with chronic pain, fatigue and may also involve mental health issues such as depression (Russell 2001; Wolfe et al. 1990, 2011). This illness was chosen because it involves long-term constant self-management practices by sufferers to manage their condition, which entails the constant need for supportive resources such as information to aid the self-management practices of these cohorts. Therefore, the study selected adults who have been diagnosed with fibromyalgia (self-reportedly diagnosed).

Also, the aim of only selecting adults with fibromyalgia was to provide a common basis for comparison of findings and account for the potential differences between each SMT included in the study (Andrade 2009; Baxter and Jack 2008; Yin 2013). For this study, the selection of these cohorts with fibromyalgia allows the researcher to gain a comprehensive overview of how these SMTs are applied to the self-management practices of adults with chronic illness.

### 3.5.1 Unit of analysis and key informants

Previous scholars have argued the importance of the unit of analysis and stated that a unit of analysis is based on the research questions for a study (Benbasat et al. 1987; Eisenhardt 1989; Walsham 1995; Yin 2013). Accordingly, the unit of analysis for the qualitative aspect of this study is the individual living with Fibromyalgia who is using social media in their illness management practice.

Two significant challenges to the application of case study approach to a social media context are: 1) defining the boundaries of the case and; 2) defining the units of
analysis (Urquhart and Vaast 2012). Accordingly, Urquhart and Vaast (2012) suggested that social media data should be contextualized and “central texts” could be collected about the cohort of interest using key terms and keywords associated with that group. Therefore, for the data analytics aspect of the study, the unit of analysis are the posts written by chronically ill individuals with fibromyalgia which were collected from each SMT.

3.6 ETHICS APPROVAL

This study required ethics approval from The University of Melbourne before data collection could proceed because it involved human participants. For the School of Computing and Information Systems (CIS), the relevant committee is the Engineering Human Ethics Advisory Group (EHEAG). A minimal risk ethics application was submitted in April 2016 and approval was received in June 2016, enabling the research to proceed. Therefore, the research reported in this study was conducted in compliance with the ethical guidelines set out by The University of Melbourne. The next section discusses the data collection and analysis approaches that were applied to the study after ethics approval was obtained.

3.7 DATA COLLECTION AND ANALYSIS

The researcher searched on Facebook, Instagram, Reddit and YouTube using the keyword: “fibromyalgia” or “fibro”. Once these groups were located, permission was sought from the gatekeepers to these online communities where applicable (Reddit and Facebook) to contact users within these communities and collect data from these communities for use in this research. This was done by sending online messages to these gatekeepers that included the plain language statement and consent forms explaining the study in general and the anticipated activities that would be carried out by the researcher or requested from informants who provided consent (see Appendix A and B). For instance, informants were expected to participate in an online interview, lasting 60 minutes or longer and allow the researcher permission to explore their posts and activities on the site concerning fibromyalgia management. The quantitative strand commenced with a similar search and involved scraping/mining of central texts from Facebook, Instagram, Reddit and YouTube. The search was constrained to texts in English, which were found upon examination to be related to managing fibromyalgia (Debortoli et al. 2016; Urquhart and Vaast 2012). Table 3.1 below summarizes the
data collected for the qualitative and quantitative aspects of this thesis, which are further discussed in each respective case study Chapter (Chapters 4-7).

<table>
<thead>
<tr>
<th>Thesis Chapter</th>
<th>SMT</th>
<th># Posts collected</th>
<th>Interviews</th>
<th>Age range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter 4</td>
<td>Reddit</td>
<td>4,272</td>
<td>11</td>
<td>24-40</td>
</tr>
<tr>
<td>Chapter 5</td>
<td>YouTube</td>
<td>1,020</td>
<td>9</td>
<td>24-37</td>
</tr>
<tr>
<td>Chapter 6</td>
<td>Instagram</td>
<td>77,843</td>
<td>10</td>
<td>21-45</td>
</tr>
<tr>
<td>Chapter 7</td>
<td>Facebook</td>
<td>11,786</td>
<td>12</td>
<td>35-69</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>94,921</td>
<td>42</td>
<td></td>
</tr>
</tbody>
</table>

To mitigate the potential skewing effects that arise from the disparity in the number of posts collected per SMT as indicated in Table 3.1 above, the researcher conducted data cleaning and reduced the SMT dataset to 700 posts per SMT for the data analytic portion of this research (Refer to Section 3.7.4 for further explanation on data sampling/reduction for the text corpus).

3.7.1 Qualitative data collection

There are numerous qualitative data collection techniques that have been applied in previous research to investigate appropriation of technologies, with studies conducted in traditional IS settings and in studies of online communities such as focus groups, interviews, observations and others (Fetters et al. 2013; Langer and Beckman 2005; Myers and Newman 2007; Schultze and Avital 2011; Yin 2013). For this study, the qualitative data collection involved using semi-structured interviews, observation, physical artefacts and research memos to gain an understanding of SMT appropriation in the chronic illness context. In this, the researcher was a neutral observer and did not participate in the interactions on the group except to recruit members for the discussion.

Semi-structured interviews

According to Schultze and Avital (2011), interviewing allows researchers to: “generate deeply contextual, nuanced and authentic accounts of participants' outer and inner worlds, that is, their experiences and how they interpret them” (Schultze and Avital 2011). The semi-structured interview used in this study allowed the researcher to co-create meanings from the perspective of study informants (Myers and Newman 2007; Schultze and Avital 2011; Yin 2013). This approach was applied to
uncover retrospective accounts of the experiences of the study’s key informants regarding appropriation of social media and its effects on their illness management practices (Myers and Newman 2007; Schultze and Avital 2011; Westbrook 1994).

First, after contact was established with potential key informants, consent forms and plain language statements detailing the research aims and expected participation from individuals who consent to partake in the study were disseminated among interested cohorts. Next, rapport was established with the informants through initial chats before the interview to minimize discomfort for these participants through establishing familiarity with the researcher and confirming their suitability for inclusion in the study (Myers and Newman 2007). The suitability criteria for these informants required that they: 1) be over 18 years of age and; 2) are diagnosed with fibromyalgia.

The interview questions were based on the research questions related to:

1) Why one or more SMT (s) are used for illness discussions;

2) How the SMT influenced their illness management practices;

3) What other issues influenced adoption and continued use of the SMT as part of their illness management practice;

4) Details on patterns or processes of how the SMT was currently used and;

5) Retrospective accounts on their specific appropriation process with the SMT.

Additionally, informants were asked how they viewed their level of self-efficacy with managing fibromyalgia based on the classification proposed by Huh et al. (2015) which characterized chronically ill adults by their illness characteristics and level of efficacy in self-managing their conditions. These levels of self-efficacy included: 1) Experienced patient; 2) Transitioning patient and; 3) Newly diagnosed (Huh et al. 2016). Experienced patient refers to those chronically ill cohorts who have an established illness management regimen due to dealing with their chronic illness for several years. Transitioning patients refer to those informants who are actively seeking to create or modify their current self-management plans through the information shared on these SMTs. Newly diagnosed refers to informants who have recently
received a diagnosis, are seeking to understand their conditions to enable them to start building an illness management plan.

Due to the geographically dispersed nature of the study informants, interviews were conducted through Skype, Gmail chat applications and through social media sites chat features such as Facebook Messenger depending on the preferences of the key informants (Schultze 2011). Each interview lasted 60-90 minutes, and a schedule had to be carefully negotiated due to the time differences caused by geographical distance. This approach allowed access to a wide range of informants while enabling them to remain within their safe, familiar environments, minimizing discomfort for them; this was particularly important given the physical and psychological toll fibromyalgia has on sufferers (Oltmann 2016).

Conducting interviews using an online synchronous strategy allowed the researcher access to a wider range of key informants appropriate for the sampling criteria delineated for this study. Still, this strategy required the researcher to create accounts on each of the four SMTs to gain access to the examined SMTs in order to access potential informants and conduct observations (Hookway 2008; McKenna et al. 2017). Another issue ingrained in carrying out online interviews concerns the potential exclusion of study informants who are not technologically savvy or who may not have access to the SMTs included in the study (McKenna et al. 2017).

**Observation**

A properly structured observation aims to avoid altering the natural behaviour of people within a research setting (Westbrook 1994). According to Yin (2013) applying a casual observation process to a case study allows the researcher to “assess the occurrence of certain types of behaviours” which could serve to enrich the insights derived from data collected via interviews (Yin 2013). Online observation was used in this study to allow the study of appropriation behaviours of the research participants on these social media tools (Konijn et al. 2013; MacColl et al. 2005). Some behaviours such as posting, and commenting could be observed, but some other actions such as lurking could not easily be observed. The researcher joined these groups and followed these profiles for the duration of the data collection period to note the activities and norms within these chronic illness communities. To minimize the potential influence on study participants, the researcher was a neutral observer and casually observed the same group of informants who consented to participate in the interviews (Walsham...
2006). With the consent of the gatekeepers where relevant (Facebook and Reddit) the researcher also casually observed the entire group to gain a general understanding of activities and norms within these types of communities.

**Physical features of SMT (digital/physical artefacts)**

Physical artefacts are one of the data collection tools available for evaluation in a qualitative study (Tsang 2013; Yin 2013). According to Yin (2013), physical artefacts such as technology could also serve as data collection sources and provide rich insights into the technical features and capabilities available to study cohorts (Yin 2013). At the start of data collection, the researcher examined the features of these social media tools to better understand their material/technical properties which are important to chronically ill users (Alaimo and Kallinikos 2017; Benbasat and Zmud 2003; Kallinikos et al. 2012; Leonardi 2012; Orlikowski et al. 2006). To this effect, the findings allowed the researcher to gain familiarity with the digital environments and explore to what extent these environments could offer various affordances or constraints to chronically ill users.

**Research memos**

The researcher also kept memos during the data collection and analytic process to document her reflections on the issues discussed with each key informant and take notes on topics that may require further expansion (Charmaz 2006; Strauss and Corbin 2008; Yin 2013). Maintaining research memos also served as an analytic exercise to expand on the researcher’s thoughts about emergent themes that were found during analysis and these memos were stored in the case database using NVivo 11 pro (Miles et al. 1979, 2014; Strauss et al. 2008; Yin 2013).

**3.7.2 Quantitative data collection**

**Data mining techniques**

According to Urquhart and Vaast (2012) “The huge volume of data that researchers can collect in social media environments create data processing, reduction, and management challenges”. Accordingly, some researchers have outlined potential strategies to guide data collection and management for IS research

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1 Findings from this observation and the resulting analysis was published in the Australasian conference on information systems (ACIS) in 2016.
with social media data including the use of data mining approaches to extract data from these sites (Barbier 2011; Debortoli et al. 2016). Accordingly, the researcher utilized the following data mining tools: Netvizz, PRAW and the Picodash service to aid the collection of user-generated social media data. Netvizz is a free-to-use tool for research purposes in the form of a browser-based data mining application that allows scholars to search and extract data from Facebook and YouTube (Rieder 2013). Netvizz returns data in a CSV format that includes textual data such as posts and comments; and interaction metrics from Facebook and YouTube. PRAW is an acronym for the Python Reddit API Wrapper which allows programmatic access to publicly available data from Reddit, which is returned by default in JavaScript object notation (JSON) format. Finally, Picodash is a paid data extraction service that collects public Instagram data for research or business purposes. These tools returned data in from the API of each SMT in which enabled further exploration of the dataset extracted from these SMTs, using Python scripts to yield deeper insight into the sentiments, topics and interactions of chronically ill adults on each SMT.

3.7.3 Qualitative data analysis methods

According to Miles et al. (2014), data management is an essential consideration for qualitative research due to the typically large amounts of data and the iterative nature of analysis. The researcher made use of NVivo 11 pro’s qualitative data analysis software to manage the case data and to conduct coding activities. Therefore, the researcher maintained a case study database which contained various pieces of data:

- Interview transcripts,
- Screenshots from each social media site,
- Contact summary sheets,
- Memos, and
- Data collection logs.

Using NVivo 11 pro allowed exploration of the dataset using the file tree to explore the various data sources contained in the project NVivo 11 pro also allowed the use of auto-coding functions to assist in the initial step of familiarizing with the collected data. The researcher adopted a two-phased approach using a mix of inductive and deductive approaches to analyse the collected data. The first phase of coding
involved an inductive approach that comprised line-by-line review of the interview transcripts open coding, using strategies like 1) descriptive coding; 2) emotion coding; 3) attribute coding; 4) process coding and; 5) in vivo coding (Charmaz 2008; Gioia et al. 2013; Miles et al. 2014; Saldana 2009).

These strategies allowed labels to be assigned to each line of interview data based on the meaning interpreted by the researcher from these data.

The next phase first involved axial coding to cluster similar themes from the collection of codes generated in the initial coding step (Miles et al. 1979, 2014; Saldana 2009). Moreover, in this stage, the researcher integrated concepts from the practice lens with the themes that were found and engaged in continual cycling between the concepts interpreted from the data. Axial coding allowed the researcher to understand the relationship between concepts from the interview data better while remaining sensitive to new findings from the dataset (Charmaz 2006; Gioia et al. 2013; Strauss et al. 2008). A benefit of this approach was that it allowed the voices of key informants to be preserved in the derived themes that emerged from the analysis activities, which is in keeping with the interpretive stance of this study. Finally, interpretive coding was applied to abstract themes to more aggregate dimensions to account for the main concepts that were found in collected data (Charmaz 2006; Gioia et al. 2013; Strauss and Corbin 2008).

The study aimed to gain a deeper understanding of how adults with chronic illnesses engage with and appropriate social media tools as part of their illness management practices. Accordingly, it was also necessary to construct matrices and network displays (using NVivo 11’s functionality) to compare the derived themes and explore the processes involved in the appropriation of social media by these cohorts (Miles et al. 2014; Yin 2013).

### 3.7.4 Quantitative data analysis methods

Similar to the qualitative data protocols, it was equally essential to maintain a data management plan for the data analytics process. Therefore, data collected through data mining and the Python scripts that were used to extract the data where applicable were stored in a private repository on BitBucket along with the associated queries. The following tools were used for the data analytic aspect:
• **Python scripting language**: Python-based packages were selected for the quantitative strand of the study because Python and the R language are the most used languages in open source data analysis and the researcher already had some experience with using Python scripting language. Also, the Python language had several libraries and ready-to-install packages that provided a development environment suitable for scientific research (Debortoli, Müller, Junglas, et al. 2016). These Python packages allowed descriptive and exploratory analysis as well as enabled the researcher to carry out data cleaning on the dataset, removing all non-English, non-text entries as a pre-requisite for the type of analysis used in the study such as topic modeling using Latent Dirichlet Allocation (LDA) or even word cloud generation.

• **Anaconda development environment**: Anaconda is a Python package for data science that includes tools for programmatic analysis of text, image and video data (Continuum Analytics 2016). It includes libraries for advanced, reproducible data analytics using tools such as the Jupyter web-based IDE and Scikit-learn machine learning library, and many more open source state of the art tools used in the data science domain (Debortoli et al. 2016; Müller et al. 2016). In this study, the anaconda environment provided tools to allow manipulation of this dataset such as Python Pandas, a library which provides some necessary data analysis functionality (McKinney 2018). Further, using the anaconda environment, the researcher was able to import the other libraries and their related dependencies for further analysis and data visualization such as Scikit-Learn for Latent Dirichlet Allocation (Pedregosa et al. 2012).

For the analytics aspect, first, basic descriptive queries were carried out on the collected text to explore the contents using some Python data analysis functions, for instance, to summarize the contents of the dataset. Following that, the collected text was cleaned using the python Pandas library to remove: non-English posts, blank posts, posts that did not contain text. This cleaning step was necessary because the methods that were to be applied to analyse the data are better suited to a text-based corpus. Next, the collected texts from each social media tool were sampled to 700 posts from 1-1-2016 until 31-8-2017 using a Python random sampling function.
Topic modelling is a data analytic strategy that uses a variety of advanced statistics and machine-learning techniques to identify dominant themes and “latent” topics through the co-occurrence frequencies of words within text corpus (Debortoli et al. 2016; Müller et al. 2016). According to Wise and Shaffer (2015) the sheer volume of social media data typically included in analysis, creates a problem for the interpretation of results when using conventional statistical analysis methods (Wise and Schaffer 2015). Hence, probabilistic topic modeling was applied to the text corpus to reduce the dataset and identify the most frequently occurring terms which were computed based on relevance or weight based on an analysis of the entire text corpus using the Latent Dirichlet Allocation (LDA) algorithm. For this study, LDA topic modelling was conducted using the Sci-kit Learn Machine Learning library and; these topics were then qualitatively coded based on overall concepts that arose from the data (Blei et al. 2003; Debortoli et al. 2016; Sievert and Shirley 2014).

Further, using LDA allowed the researcher to induce meanings and themes from this text corpus based on generated topic clusters. Subsequently, the final step of the data analytics strand involved coding based on the practice lens of the study (refer to Chapter 2, Section 2.6.3), which was also abstracted to aggregate dimensions and then integrated with the qualitative findings.

3.8 ASSESSMENT OF THE RESEARCH DESIGN QUALITY

Previous scholars have proposed several strategies to enhance quality, credibility or rigor of case study research for interpretive (Darke et al. 1998; Gioia et al. 2013; Strauss and Corbin 2008; Walsham 2006), critical realist (Bygstad and Munkvold 2011; Wynn and Williams 2012) and positivist (Dubé et al. 2003; Eisenhardt 1989; Yin 2013) research perspectives with the goal of safeguarding quality of the conducted research. For this study, the eight strategies below were informed by research literature and applied during the research process to control for quality:

1. **Theoretical sampling:** As described in Section 3.5, sampling was theoretically driven to select chronically ill adults who were current users of social media for illness management purposes (see Appendix A, B and C) (Charmaz 2006, 2008; Eisenhardt and Graebner 2007; Strauss and Corbin 2008).
2. **Researching in the field/prolonged engagement in the field:**

   Participant recruitment was conducted through these SMTs and where possible, interviews were carried out through the chatting function of each SMT (Yin 2013). Additionally, the researcher had accounts on the selected SMT tools to observe the features of the tools and the actions of the key informants on these sites for the duration of the study. Because of prolonged engagement, the researcher could view activities of others on each SMT and so derive a deeper understanding of the research context.

3. **Triangulation through multiple sources of evidence:** In this study, the use of multiple sources of evidence allowed data triangulation which helped the researcher gain reliable insights into the influences, processes and affordances of appropriation of each SMT for chronic illness management (Denzin 2012; Yin 2013). As discussed earlier in the Chapter, (see Section 3.7).

   Data was triangulated from multiple sources, including: Semi-structured interviews; observations; analysis of the physical artefacts (the social media tools) and; text corpus collected from each social media tool. For this study, the text corpus collected from social media was used to explore the general themes in this context. Conversely, the qualitative dataset was assigned more weight because it provided a deeper richer explanation for findings from the quantitative dataset.

4. **Use of a case study database:** The researcher stored case documents such as interview transcripts, memos and the contact summary forms in Nvivo 11 plus as a way to organize and keep track of the data generated during data collection and analysis for this study (Miles et al. 2014; Yin 2013). Data collected through the API were stored as on a BitBucket repository including the related Python scripts that were written to analyse these data (see Appendix C, D and E). Also, the researcher also collected and stored screenshots of each SMT during data collection to preserve a snapshot of the design and features of these SMTs. Maintaining a cases study database was important because digital sources of information are subject to frequent updates and could easily
be inaccessible to the researcher (McKenna et al. 2017; Urquhart and Vaast 2012; Yin 2013).

5. **Maintained a chain of evidence for auditability/reliability**: Findings from the case studies reported in Chapters 4-7 provide evidence in the form of rich description, quotes and screenshots to provide a basis for findings and conclusions drawn from the present study (Strauss et al. 2008; Yin 2013).

6. **Peer debriefing through case study meetings and presentations**: The researcher had frequent case meetings (Yin 2013) with supervisors to discuss findings from each case study at length. These meetings were conducted fortnightly during the data collection period (from June 2016-November 2017). Further, the researcher presented case study findings with the broader IS research community during seminars at The University of Melbourne and at conferences, which helped to validate the plausibility of insights derived from the present study.

7. **Development of thick descriptions**: Previous scholars have stressed the importance of rich contextual descriptions in qualitative study as a way to present findings from the perspectives of study informants (Strauss and Corbin 2008). Accordingly, the strategy applied by the researcher was crafted to retain the perspective of key informants and capture the richness of the research context to confirm the validity of interpretations presented in this present study (Myers 1998; Strauss and Corbin 2008) (Refer to Section 3.7).

8. **Replication for generalizability**: Replication in this present study allowed the researcher to observe themes that were common or unique among the case studies. Because this study is designed as a multiple case study, its findings could be generalized to similar contexts to investigate appropriation of SMTs to manage other chronic diseases such as diabetes or endometriosis (Eisenhardt 1989; Miles et al. 2014; Yin 2013). It is worth noting that generalizability in the present study does not focus on causality in the positivist form. Instead, this study focuses on general patterns to enhance contribution to theory, generation of concepts and rich theoretical insight (Myers and Klein 1999; Walsham 1993).
3.8.1 Limitations of the research design

Despite careful construction of the research design, the researcher notes some limitations, such as:

1. **The extent of observed behaviour in the conducted study**: Given the nature of social media tools it is challenging to observe actions of individuals that are undertaken privately such as lurking or privately chatting with other chronically ill cohorts. For instance, actions, like lurking or messaging carried out by members in the examined SMTs, could not be examined by the researcher. Consequently, the researcher had to rely on the appropriation behaviours reported by study informants.

2. **Reliance on retrospective accounts**: The study informants had already adopted the examined SMTs at the time data collection had commenced. Therefore, antecedent influences on the adoption of the examined SMTs could be subject to recall bias.

3. **Gender and under-representation of male key informants in qualitative portion of the study**: The present study has significantly more female key informants (38 of 42) than male key informants (4 of 42). Moreover, the majority of study participants were located in the USA. This outcome was not a research design choice, rather it was a consequence of the sampling and participant recruitment strategy applied to conduct this study. For instance, in the Facebook case study the groups that were used as recruitment platforms also included men, but they did not respond to calls for participation. Further, to address the limited number of male participants, the researcher also contacted a male only group for men with fibromyalgia to participate in the research but there was no response from the gatekeepers (admins and moderators). Similarly, on the other SMT tools (Reddit, YouTube, Instagram) the researcher kept the recruitment efforts broad and tried to include male informants with limited success. Ultimately, the gender distribution in the present study reflects the individuals who consented to participate in the study. Accordingly, it is possible that a sample with mostly male, or equal representation of male key informants may yield additional insights not captured in the present study.
3.9 SUMMARY

This chapter provides a description and exposition of the research design applied to this study. Following an interpretive approach, this research is designed as a multiple case study using mixed methods with the aim to better understand social media appropriation by chronically ill adults to make more sense of and improve the management of their illness. The selected research design made use of qualitative coding practices which were both inductive and then deductive through the sensitizing device of the study’s practice which led the conducting each case study as reported in the next four chapters. The following chapter presents key findings from the Reddit case study with mixed methods.
Chapter 4: The Reddit case study

Illustrative quote: “I joined Reddit for funny pictures and cute animals. I quickly discovered it was so much more than that - it was a huge resource of information and personal experience on just about any topic imaginable. I joined officially five years ago after lurking for 2 - 3 years. I latched onto the Fibromyalgia (subreddit) when I was finally diagnosed after living in hell since I was young (5 years old or so when my symptoms showed up). I am active on about 2 - 4 subreddits. Fibromyalgia being number 1, and then it is a toss-up between /r/askReddit and a few others.” (Reddit02).

INTRODUCTION

In the previous Chapter 3, the research design for the thesis was discussed and justified as sufficient to guide investigation on how adults with chronic illnesses engage with and appropriate social media tools as part of their illness management practices. Accordingly, this chapter presents the key findings from the mixed methods analysis of the first of four cases that address our main research question: How do chronically ill adults engage with and appropriate social media tools to better understand and manage their illness? This chapter proceeds by outlining the background and relevant history of Reddit Social Media Tool (SMT) in Section 4.1. Next, Section 4.2 outlines the specific data collection strategies applied for the Reddit case study, including an overview of key informants and their antecedent experiences to the appropriation of Reddit. Subsequently, key findings are presented in Section 4.3; demarcated into three main dimensions: 1) process of appropriating Reddit for illness management; 2) individual incentives for adoption and continued use of Reddit for chronic illness management and; 3) effects of the Reddit SMT environment on appropriation for chronic illness management. The Chapter concludes with a discussion in Section 4.4 and outlines affordances which act to enable or disrupt appropriation of Reddit for chronic illness management.
4.1 CONTEXT OF THE CASE

4.1.1 The Reddit social media tool: A brief background

Reddit was created by Steve Huffman and Alexis Ohanian in 2005 and is a social network site that prioritizes news aggregation, content rating and discussions among members of its online community. In addition, Reddit was acquired by Conde Nast publications in 2006, although it continues to operate as an independent company (Fiegerman 2014; Robinson 2017). Further, Reddit is currently ranked as the 11th most popular social media site globally and reportedly had 330 million active users while it was recently ranked as the 3rd most visited websites in the world (Booth 2018; Statista 2017).

The Reddit technology suite consists of an official desktop website and a mobile application. Reddit also provides an Application Programming Interface (API) integration endpoint for developers of services that integrate with or use some of the functionality from the site. At its core, Reddit functions like a bulletin board system, posts are displayed and ordered based on popularity (number of likes, dislikes, upvotes and downvotes). Content on Reddit is curated into streams of user-created boards called ‘subreddits’ which are all centred on general, high-level topics for instance (r/Christianity). For example, Figure 4.1, below illustrates the landing page of Reddit which displays a selection of the most popular posts from all subreddits in Australia (curated by location).

Figure 4.1: Example of the Reddit landing page
Reddit’s vision statement is reflective of the community-focused nature of the website: “Reddit bridges communities and individuals with ideas, the latest digital trends, and breaking news (...okay, and maybe cats). Our mission is to help people discover places where they can be their true selves and empower our community to flourish.” (Reddit 2016). Additionally, Reddit has several core features that support the overall company goal of openness and diversity of perspectives; for example, users may subscribe to subreddits, submit posts; submit comments to posts; upvote or downvote posts and comments within a subreddit. Downvotes are equivalent to disliking a post and reduce the visibility from the r/Fibromyalgia main page. Similarly, upvotes are equivalent to likes and serve to boost the ranking of the post and its visibility on the r/Fibromyalgia main page.

The overall score of the post is determined through subtraction of its downvotes from upvotes, these combine to control the ranking of the post on the r/Fibromyalgia main page and influences the user’s reputation which is termed “Karma”. Moreover, Reddit is free to join, and account creation does not require email validation, which lowers the barrier of entry for users globally. Additionally, access to user profiles, subreddits, posts and comments are open to anyone with an internet connection. Table 4.1 below, summarizes some of the core features of Reddit.

<table>
<thead>
<tr>
<th>Feature</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reddit account</td>
<td>A Reddit account gives the user access to create posts on the site, comment, upvote and downvote content. A user may create as many accounts as they wish to on Reddit, as including an email is not necessary for account creation, as a result, some users create “throwaway accounts” to make posts or comments separate from their main account. An account is not needed to access the majority of the Reddit content, including posts, comments and viewing user accounts on the site. However, an account and login are required to access hidden subreddits.</td>
</tr>
<tr>
<td>Profiles</td>
<td>A Reddit profile offers a summarized version of a Reddit account’s activity on the site. It includes the posts submitted by that account, comments submitted by the account and other information on the account’s status such as the duration of membership on the site and a profile’s karma.</td>
</tr>
<tr>
<td>News/Activity Feed</td>
<td>The news feed keeps the account informed on the recent and most active submissions across the entire site. The main pages for news feeds are: r/frontpage which displays all the latest posts across the site and r/home which displays the latest posts based on the user’s subscribed subreddits.</td>
</tr>
</tbody>
</table>
### Table 4.1 A sample of core features on Reddit SMT relevant to the case study

| **Subreddits** | Subreddits are virtual rooms centred on a topic of interest. Any Redditor with an account may post in any subreddit. Majority of subreddits (or subs) are public, but there are a few subs that are hidden and known only to members (membership by invitation only). To create a subreddit, the account must meet two criteria set by the site: be at least 30 days old and; have an undisclosed minimum amount of positive karma. In general, each has a set of rules that are laid out in the sidebar and a moderating team of users who volunteer to act as administrators of the subreddit, ensuring that posts and comment comply with the rules laid out in the sidebar. |
| **Karma** | Over time, accounts with numerous posts or comments accumulated, may receive upvotes or downvotes for their content. These accumulated points are known as “karma”. Karma could be a negative or positive value, depending on the total generated from the calculated points. |
| **Upvote** | Upvote is a point system used on the Reddit website which allows users to signal their approval or support for a post or comment. Upvotes move a post towards the top of the site, and they are an indicator of the number of people who support the content in a post. |
| **Downvote** | Downvotes are part of the point system used on the Reddit website which allows users to signal their disapproval for a post or comment. Downvotes move a post towards the bottom of the site and indicate disapproval. |
| **Score** | A post's score is simply the number of upvotes minus the number of downvotes. If five users like the submission and three users don’t, it will have a score of 2. |
| **Chat/private messaging** | The private messaging feature allows the account to engage in private conversations with other accounts on the site. |

Reddit’s popularity can be credited to its heterogeneous user base, who engages in activism for politics, education, altruism; net neutrality, cannabis legislation and other global issues (Herkewitz 2013; O’Gara and Garcia 2013; Smith 2015). For example, Reddit has played a significant role in politics in the United States; e.g. it was instrumental in the political campaigns of Donald Trump and Barack Obama (Hempel 2015; Jeffries 2012; Kobie 2017; Lopez 2016; Mendoza and Kelly 2012). The next section outlines the data collection and analysis strategies carried out for this case study (see Chapter 3 Section 7 for more detail).

### 4.1.2 Being chronically ill on Reddit: challenges of living with fibromyalgia

Fibromyalgia is a chronic pain condition which presents with other conditions such as chronic fatigue, depression, anxiety and other illness (Russell 2001; Wolfe et al. 1990, 2011). It is a long-term illness without distinctive symptoms which results in it being termed an invisible illness by its sufferers. Currently, it reportedly affects 3-6% of the world’s population, and is considered to be more prevalent in women than men (Matallana 2018; Russell 2001; Taylor et al. 2016; Wolfe et al. 2011).

During data collection, as the researcher got familiar with the Reddit fibromyalgia spaces, it was observed that these cohorts appeared to experience severe
challenges in getting diagnosed due to the nature of fibromyalgia. Key informants were assigned pseudonyms such as Reddit01, Reddit11 etc to preserve their privacy as stated in the project ethics application form (see Chapter 3, Section 3.6). Moreover, key informants shared that they typically spent numerous years suffering from fibromyalgia illness before they obtain a diagnosis.

Since there are no specific diagnostic tests for fibromyalgia, diagnosis is through a process of elimination that may span years for these cohorts. In addition, an informant discusses how, despite getting diagnosed early, she faced disbelief and ridicule from family: “This is going to sound rather sad, but for the most part my family didn't believe it was a legitimate thing back then (and especially because I was ‘too young to get it’)” (Reddit04). She also disclosed how the stigma of having a chronic illness influenced how and when she joined the fibromyalgia subreddit: “I joined Reddit about five years ago. I didn't join the fibro subreddit until I graduated college and moved overseas to Japan (where I now live.) I actually didn't really talk about it UNTIL I moved to a foreign country to ‘start over’ so to speak” (Reddit04).

4.2 DATA COLLECTION AND ANALYSIS

The qualitative portion of Reddit’s data collection commenced with a search on the website using the Reddit search bar for the terms: “fibromyalgia” and “fibro” (see data collection protocol in Chapter 3, Section 7.1). The search returned results containing a combination of posts and subreddits containing the term “fibromyalgia”: there were 3 subreddits about managing ‘fibromyalgia’ in total and most of the posts belonged to the biggest subreddit for fibromyalgia r/fibromyalgia. Next, these subreddits were assessed to enable the researcher to get familiar with the content and identify the gatekeepers from whom to seek permission for participant recruitment.

Contact was established by sending messages, using the messaging feature to the subreddit’s (r/Fibromyalgia and r/Fibro) moderating team(s) to seek permission to recruit members of the fibromyalgia subreddit for the study. Once permission was received, the researcher sent messages to 30 randomly selected profiles which had submitted posts in these subreddits, because their posts indicated that they had fibromyalgia. Additionally, the researcher made a post with permission from the subreddit moderator to request participants and 2 key informants were recruited from that post. From the 30 profiles contacted, only 16 responded - 7 declined due to ill
health and 9 profiles indicated their willingness to participate in the qualitative data collection, i.e. the semi-structured interviews and having their profiles and activity observed for the duration of the study. Consequently, there were 11 key informants in total for the qualitative portion of the study. Table 4.2 below, outlines the characteristics of the key informants from the qualitative portion of this study as indicated below.

<table>
<thead>
<tr>
<th>Key informant</th>
<th>Sex</th>
<th>Age Group</th>
<th>Location</th>
<th>Reported level of self-efficacy with illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reddit01</td>
<td>Female</td>
<td>20-25</td>
<td>United States</td>
<td>Transitioning patient</td>
</tr>
<tr>
<td>Reddit02</td>
<td>Female</td>
<td>25-30</td>
<td>United States</td>
<td>Experienced</td>
</tr>
<tr>
<td>Reddit03</td>
<td>Male</td>
<td>20-25</td>
<td>United States</td>
<td>Experienced</td>
</tr>
<tr>
<td>Reddit04</td>
<td>Female</td>
<td>30-35</td>
<td>Japan</td>
<td>Experienced</td>
</tr>
<tr>
<td>Reddit05</td>
<td>Female</td>
<td>25-30</td>
<td>United States</td>
<td>Experienced</td>
</tr>
<tr>
<td>Reddit06</td>
<td>Female</td>
<td>25-30</td>
<td>United States</td>
<td>Transitioning patient</td>
</tr>
<tr>
<td>Reddit07</td>
<td>Female</td>
<td>30-35</td>
<td>United Kingdom</td>
<td>Newly Diagnosed</td>
</tr>
<tr>
<td>Reddit08</td>
<td>Female</td>
<td>40-45</td>
<td>Australia</td>
<td>Experienced</td>
</tr>
<tr>
<td>Reddit09</td>
<td>Female</td>
<td>25-30</td>
<td>United States</td>
<td>Experienced</td>
</tr>
<tr>
<td>Reddit10</td>
<td>Female</td>
<td>25-30</td>
<td>United States</td>
<td>Transitioning patient</td>
</tr>
<tr>
<td>Reddit11</td>
<td>Female</td>
<td>40-45</td>
<td>United States</td>
<td>Newly Diagnosed</td>
</tr>
</tbody>
</table>

These key informants were assigned pseudonyms such as Reddit01, Reddit11 etc to preserve their privacy as outlined in Chapter 3 (Section 3.6); Reddit02 was also a moderator. There were 11 key informants in total and 8 were based in the United States, 1 informant was from Australia, 1 was from Japan and 1 was from the United Kingdom. For the quantitative aspect, the researcher selected the r/Fibromyalgia subreddit which had a total of 9,618 subscribers and was ranked at 8,146th most visited out of the 1,209,754 total subreddits on the site at the time of data collection. Additionally, the researcher used the Python library for Reddit (PRAW) version 5.4.0 to retrieve data from the r/Fibromyalgia subreddit.

In total, 4,272 posts from January 2015-January 2017 were collected for this study’s analysis as stated in the data collection protocol outlined in Chapter 3, Section 3.5.2 (Rieder 2013). This query returned a JavaScript Object Notation (JSON) flat file containing data about posts from the subreddit containing information such as post title, post content, username, comments and interaction metrics (upvote, downvotes, number of comments etc). Next, the researcher conducted data cleaning to remove duplicate items and this dataset was reduced to 700 individual posts and related comments as part of data cleaning using random sampling techniques on python.
Analysis followed the protocols outlined in Chapter 3, (see Section 3.5 for more information on data collection or see Section 3.7 for analysis protocols).

4.3 FINDINGS

The findings from the Reddit case study are demarcated under three broad categories: 1) process of appropriating Reddit for chronic illness management; 2) individual incentives for adoption and continued use of Reddit for chronic illness management; and 3) effects of the Reddit SMT environment on appropriation for chronic illness management, each described in the next sections.

4.3.1 Process of appropriating Reddit for chronic illness management

Key informants stated that initially they had surfed the internet and browsed various subreddits before signing up/creating accounts on Reddit. For example, one informant (Reddit10) stated that she adopted Reddit in general and r/Fibromyalgia after seeing screenshots from it on Imgur:

“I saw a bunch of screenshots on Imgur from Reddit, I joined because I thought it was fun. I liked how you could read about anything you wanted, and the layout was nice” (Reddit10).

All key informants confirmed that they had joined the fibromyalgia subreddit after they had already been diagnosed with fibromyalgia. As an informant explains:

“I’ve explored Reddit for a few years, but when I got sick, I decided to join so that I could find other people with my similar diseases and seek advice” (Reddit01).

Reddit is comprised of a group of virtual rooms where members may interact at different levels as indicated in Table 4.3 below. Data from the text corpus showed interaction metrics for posts such as number of comments, downvotes, upvotes and overall score. As indicated in Table 4.3, it appears that activity on Reddit is commenting on posted content, however, data provided from the Reddit API does not include the number of views each post may have attracted.

| Table 4.3 Reddit dataset descriptive statistics for appropriation actions for each post |
|-----------------|-----|---------|----------------|---|---|---|---|
| Variables       | Count | Mean   | Standard Deviation | Min | 25% | 50% | 75% | Max |
| Comments        | 700   | 11.56  | 9.57             | 0   | 5   | 9   | 16  | 68  |
| Downvotes       | 700   | 0      | 0                | 0   | 0   | 0   | 0   | 0   |
The next most common action is liking; it should be noted that the Reddit API does not provide access to downvote metrics, for example in Table 4.4, the value for the downvotes row is 0. Nonetheless, the score value may be used as a proxy to determine if there were any downvotes, in the dataset, it appears that there were no downvotes in the selected text-corpus. Based on the limitations of the text corpus to demonstrate the processes of appropriation, it was important to explore elicit appropriation processes from key informants. The next section outlines qualitative themes to provide more insight into the intricacies of appropriation for these cohorts. There are 5 main themes for process of appropriation demarcated into: 1) lurking and daily participation on Reddit; 2) commenting and upvoting to show support; 3) adaptive appropriation of multiple subreddits; 4) customizing experience of Reddit through community-built plugins and apps and; 5) complementarity and borderless appropriation of SMTs for illness management, each described below.

1. **Lurking and daily participation on Reddit**

Several informants discussed the frequency of their interaction on Reddit and the form of interactions they practiced. The majority of the key informants indicated that they were on the subreddit multiple times a day as an informant explains:

“I'd say I'm active on Reddit for about 30 minutes -1h a day mainly reading, not posting or commenting” (Reddit09).

Although they were on the subreddit multiple times a day it was observed that they mostly read content as an informant explains:

“I'm more of a lurker, I don't really post much I just check Reddit a lot during the day, like 10 times a day minimum - if I'm bored at work, I'm on Reddit all day” (Reddit10).

2. **Commenting and upvoting to show support**

Most informants indicated that they often commented to help others and make sure that all relevant posts have at least one response, as an informant shares:
“I usually browse Reddit twice a day. I like to make sure that posts with low activity get at least one answer, and people who seem very desperate. I just feel a lot of empathy and want to help in any way I can” (Reddit01).

For some informants (4 of 11), along with commenting, they also reported that they interacted the most through upvoting for similar reasons; to support and encourage interaction with posts that had low activity:

“I've posted four times in the last three months and have commented 21 times in that period - though I do upvote posts where I don't think I personally can help but I do want to support and hear more about/from” (Reddit07).

3. Subscription to multiple subreddits

It was observed that most informants were subscribed to numerous subreddits, but their activities on each subreddit varied significantly; Some prefer to lurk more on other subreddits:

“Oh man, I don't know what qualifies as "active". I lurk a lot on the "base" subreddits people automatically are subscribed to. I like "r/AskReddit", "r/WorldNews", and "r/Science" a lot. But I don't comment there a lot. Just reading” (Reddit04).

While other informants report being active on other subreddits with varied focus; yet all informants indicated that they interacted most comfortably within r/fibromyalgia:

“T'm active on about 2-4 subreddits. /r/Fibro being #1, and then it's a toss-up between /r/askReddit and a few others. oh, totally there is a huge difference. I am pretty active on /r/TrollXChromosomes and that's my sarcastic, silly, snarky sort of outlet” (Reddit02).

4. Customizing experience of Reddit through community-built plugins and apps

It was observed that there are several open source browser skins and mobile applications which may be used to enhance the interface of the site, which were built by members of the community and available in free and paid versions. A few informants (3 of 11) enhanced their version of Reddit through these skins to add additional functionality to their Reddit experience. An informant explains:
“I use the Reddit enhancement suite add-on for google chrome and I also use Flux/night mode on my computer always because I get migraines often. It allows me to do less clicking, with it, Reddit just scrolls, and the images appear on the comments page, instead of my having to click over to the Imgur website etc. Also, If I tag someone then I can see when he posts a new thing.” (Reddit04).

5. Borderless appropriation of SMTs for illness management

Informants also reported that they had adopted several other SMTs for illness management. Some of these SMTs are specific to health from sites such as patientslikeme.com, inspire.com, mdjunction.com and others. Key informants indicated that these tools were used to augment their participation with similar others, as one informant explains:

“I also use ‘mdjunction.com’. I have briefly used ‘patientslikeme.com’ and ‘inspire.com’, but I am no longer active on those sites. Oh, and Tumblr! Tumblr is just for fun. ‘Mdjunction’ is similar to how I use Reddit. To help others chronically ill patients” (Redditor01).

It appeared that although these informants had accounts on several other sites specifically for illness management purposes, they found the fibromyalgia subreddit to be more valuable for their illness management needs. Furthermore, as the informant above explained, they also appropriated other SMTs sometimes for hedonic reasons or as part of their illness management practices to differing levels of effectiveness, as another informant explains:

“I tried joining a website called healthunlocked.com but it didn't feel anywhere near as personal. I don't really like posting my health stuff on Facebook either as I've heard people mention about others "constantly whining" about health. Reddit just tends to be my safe place where I can be completely honest without having to worry about judgement” (Reddit07).

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2. https://chrome.google.com/webstore/detail/Reddit-enhancement-suite/kbmfpngjigdilneigpgjifpgocmfgm
4.3.2 Individual incentives for adoption and continued use of Reddit for chronic illness management

Individual incentives refer to personal needs that prompt adoption of Reddit for illness management by study informants. As the first step in analysis, the Reddit text corpus was explored for word frequencies, to assess the main topics that occurred in the collected content as illustrated in the word cloud (Figure 4.2 below). The word cloud indicated that the most frequently occurring words were: pain, doctor, fibro, know, feel, etc. These terms indicate that the collected text were discussions about these cohorts’ experience of fibromyalgia.

![Word cloud](image.png)

Figure 4.2 Word cloud illustrating the most frequently appearing words in the Reddit dataset

Next, to gain more meaningful insight, topic modelling was conducted on the text corpus using latent Dirichlet allocation (LDA) algorithm to extract the 50 most salient topics, represented through 10 terms per topic. Table 4.4 below demonstrates themes that were identified from the topic clusters derived LDA analysis of the Reddit text corpus. These demarcate the extracted topics into: (1) Seeking understanding from others (44%), (2) Seeking information from others (44%) and (3) Prompting community interaction (12%).

While LDA results provided a high-level view on the main topics that occur in the fibromyalgia subreddit, it was important to gain the perspective of key informants on their incentives to adopt and continually use Reddit.
### Table 4.4 Topic modelling results latent Dirichlet allocation (LDA)

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sample sentence from Reddit dataset</th>
<th>Sample LDA topic group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeking empathy from others:</td>
<td>“I just kind of need to vent I’m feeling really alone in my struggles with fibro I’m supposed to be at work in a few hours, but I’m so upset that I can’t sleep I’m having a bit of a flair and things at work haven’t helped the situation at all”</td>
<td>reduce shopping fun sitting listen frustrating seriously afraid heart gotten</td>
<td>44</td>
</tr>
<tr>
<td>Seeking information from others:</td>
<td>“So the last years have been a nightmare to get a reliable doctor or diagnosis I’m stuck on a very subpar health management organization (HMO) I’d like to be taken seriously. I’m just not really sure what the right questions to ask are to either get diagnosed or a referral to someone that can do that switching doctors means switching networks which is a multi-month somewhat unpredictable ordeal I don’t know if anyone here can relate or has any meaningful advice”</td>
<td>hour confirmed history dropped bought hit site referral question explained</td>
<td>44</td>
</tr>
<tr>
<td>Prompting community interaction:</td>
<td>“Hey all I have to take a sick day today because I came down with something so my accomplishment is just making this post at all! how are all of you doing what are you proud of this week anyone get their holiday shopping done yet”</td>
<td>daily accomplishment slowly current appreciated control hello able link favourite</td>
<td>12</td>
</tr>
</tbody>
</table>

The following section unpacks the two corresponding overarching qualitative themes (each with its own sub-themes) are outlined below, demarcated as: information support exchanges and emotional support.

1. **Information support exchanges: Collective sensemaking and illness advocacy**

In general, these cohorts subscribed to several subreddits to learn more and exchange information on various aspects of their illness. Key informants indicated that they were
also subscribed to other subreddits in the Reddit “health network”\(^3\) to learn more about various aspects of their illness because fibromyalgia often presents with multiple conditions. For example, some (7 of the 11) informants were also subscribed to \(r/\text{Depression}\) because depression is one of the mental health conditions that majority of fibromyalgia sufferers experience. The fibromyalgia subreddit description indicated that it is a space for sharing non-verifiable medical advice, yet it seemed to be an opportunity for members to learn what symptoms they could attribute to the illness. The fibromyalgia subreddit gave members the opportunity to learn about various facets of fibromyalgia and its typical progression, facilitating an exchange of information among members. A moderator shared her opinion on the information exchanges on the subreddit, stating:

“I think the subreddit is influential for most people on there, though. I do know that a ton of people share info on meds, doctors, symptoms, etc. and it’s super helpful for readers—especially those newly diagnosed” (Reddit02).

For the more experienced members of the subreddit such as Reddit02 and Reddit03 it was an opportunity to help others based on what they had learnt over the course of coping with their illness. These informants shared that they also exchanged information about medical tests, coping strategies, side effects of medications and other issues such as obtaining disability pensions. An informant explains the importance of these activities:

“Since fibromyalgia is so under-researched, people are constantly asking questions and trying to figure out if there’s something else they can do to improve their situation” (Reddit07).

The following section outlines the two main sub-themes of information support: i) collective sensemaking to learn and cope with fibromyalgia and; ii) illness advocacy to obtain better care outcomes.

i. **Collective sensemaking to learn and cope with fibromyalgia**: Because fibromyalgia is a chronic illness that seems to change its symptoms over time, the other health subreddits in general including \(r/\text{Fibromyalgia}\) subreddit act as a space for collective sensemaking to discover how to adapt to these changes. Some key informants (4 of the

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\(^3\) A selection of subreddits that are centred around health management and medical topics
11) also revealed that these exchanges involved gaining recommendations on whom to visit for medical care, such as what hospitals to go to, what type of medical professional to request to gain either a diagnosis or specialized treatment. For example, an informant revealed that her GP refused to treat her for fibromyalgia and so she asked members of the subreddit to recommend a general doctor who would be willing to treat her conditions. An informant explains:

“I had gotten good advice (from Reddit) about seeking help at teaching hospitals as they would have better resources and doctors that had seen more rare diseases. I did end up going to Johns Hopkins, and that was helpful in some ways” (Reddit01).

This activity is particularly helpful for informants who have other barriers to obtaining care like living in a different country. An informant (Reddit04) shared that because she lived in Japan, she was able to find a GP who believed her, but the illness is less known in that country. That informant (Reddit04) also disclosed that collective sensemaking helped saved her life and helps to protect her from dangerous, potentially life-threatening side effects of medication that she is prescribed to manage her condition.

She explains:

“This September, I was in the ER from a rare condition called "Serotonin Syndrome" because of a doctor's negligence. This syndrome has been well known in the U.S. for a while now. The sub helps me to know about what dosages people start on in the U.S., and what kind of side effects they personally have had. So, I can carefully keep it in check.” (Reddit04).

The theme of collective sensemaking is not applicable for all members as some (2 out of 11) informants indicated that due to their personalities and experience with the illness, they do not find most of the information exchanged to be applicable to them. An informant explained his frustrations, stating:

“What I get from the subreddit is information recycled, exercise, move, meditate...pray for pain killer or death” (Reddit08).

ii. Illness advocacy to obtain better care outcomes: Because fibromyalgia is not well understood, and a diagnosis occurs through a process of elimination, most of
the key informants felt that they had to advocate for their care with their GPs and other healthcare service providers as an informant explains:

“Well fibro is still so vague for doctors, that I listen to others more than my doctor. They're not at all (doctors are not familiar with fibro). Yeah you have to be your own advocate and doctor most of the time with fibro. It's awful. Like, I have a marketing degree, not a PhD haha” (Reddit06).

For most informants (6 out of 11), the illness advocacy theme extended from active participation in designing treatment plans to manage fibromyalgia symptoms to taking printouts of conversations from the subreddit to doctor appointments for consideration in relation to their health. For instance, one informant shared how she makes use of the subreddit to learn about others’ treatment and medication plans, which she then takes to her doctor to facilitate the design of an effective care plan for her (she is based in Japan). Another informant confirms this, stating:

“At the doctor I may ask about symptoms I saw on the subreddit to confirm that they are or aren't related to my condition. Doctors will usually advise me to report any new symptoms even if they seem related to old or chronic ones” (Reddit03).

For some other key informants (5 out of 11), the subreddit did not have any tangible impact on their fibromyalgia care as they were confident in the capabilities of their GPs or had taken their care into their own hands. Still, they found the coping strategies shared by others to be useful to their illness management practices. An informant explained further, stating:

“I'm in the UK I have an NHS GP and rheumatologist and I trust them both with taking on what I've said and suggesting the best course of action re: medications, physiotherapy etc. But for coping mechanisms, seeing what works for others is great - that and the general attitude help, the sub has been teaching me to care for myself when it comes to my health and to worry less about being judged by others” (Reddit07).

2. Emotional support exchanges: Stigma, compartmentalization and social support

Reddit offered space for an exchange of emotional support for these individuals, all key informants explained that living with fibromyalgia was a very isolating
experience. When asked to elaborate, they indicated that living with fibromyalgia was a very limiting experience because of constant pain, physical limitations and mental health conditions that were not well understood even by well-intentioned family members. Participation through the subreddit allowed them to be accepted and empathized with, by similar others. Exchanges of emotional support allowed members to interact with others who could relate to their limitations which helped them feel understood and empowered. An informant explains:

“It's an outlet for me to feel helpful. I also like not feeling alone. I like reading random things from strangers across the globe who experience the exact same obscure things I never thought I could relate with anyone else.” (Reddit02).

The emotional support theme has the following four subthemes: i) Dealing with illness stigma; ii) compartmentalizing fibromyalgia from real life; iii) virtual friendships and social support; and iv) discrepant emotional support exchanges.

i. **Dealing with illness stigma:** The fibromyalgia subreddit offered these cohorts a space of freedom from constant stigma. Numerous posts on the subreddit demonstrated frustration with family, friends and general practitioners who did not believe the experiences of these cohorts. Particularly because fibromyalgia diagnosis is through a process of elimination, there appeared to be a sense of stigma which caused these people to be judged by others. This seemed to cause some informants to only freely talk about their illness on the subreddit, an informant explains:

“I don't like talking about fibromyalgia in public. I'll get accused of lying a lot because I don't “look sick” And it gets old quickly; Especially on Facebook” (Reddit10).

Key informants also shared that they experienced this stigma even on other health-related subreddits. For example, an informant explains:

“I had posted once on the subreddit r/askdocs (I think that's it), and I got one person telling me that I didn't have a disease and that I should stop going to doctors for help” (Reddit01).

ii. **Compartmentalizing fibromyalgia from real life:** Despite having varying access to offline support, most key informants (6 out of 11) reported feeling guilty about requiring significant emotional support to cope with their illness. Therefore, they
made use of the fibromyalgia subreddit to gain the support they need. When asked how this differed from their offline support systems an informant shared:

“My support network outside of Reddit is my friends and family. I tend to find that no matter how lovely my real-life support system is, I end up feeling guilt talking about myself and my health so often. At least on the subreddit people are choosing to be there, and if they don't want to read something they don't have to.” (Reddit07)

iii. Online friendships and social support: The fibromyalgia subreddit offered an opportunity for people to form virtual friendships. Most (6 out of 11) key informants indicated that they had developed close friendships with other members of the subreddit, exchanging other social media contact details and mobile phone contact details, becoming close friends. When asked about the extent of these relationships however, participants stated that these friendships did not extend to an offline context. The others however preferred to engage in social support through the safety of the subreddit space. One informant (Reddit05) suggested that because most Redditors are younger, she saw little point in interacting with them outside the confines of the subreddit. This sentiment was echoed by another informant who explained:

“As of yet though I haven't talked to any of them outside of Reddit, I grew up in the era of "don't tell anyone your name or they will rob your bank account or murder you" rofl, its still a little ingrained in there even though it's daft as I use my real name for my work, and that is advertised online” (Reddit07).

iv. Discrepant emotional support exchanges: For some, these exchanges were also an opportunity to meaningfully contribute to uplifting others despite their debilitating illness. For example, the moderators set up a weekly accomplishments event, where members could post achievements to celebrate like: being pain-free for a period, completing household chores, professional accomplishments or self-care. An informant explains:

“The subreddit triggers positive emotions for me, when I comment on someone's post who is down or angry or frustrated, because I will hope that what I say will make them feel better” (Reddit02).
However, key informants shared that these exchanges were unequal and indicated that there seemed to be numerous requests for emotional support and a few (4 out of 11) key informants indicated that it caused the r/Fibromyalgia subreddit to have a depressive, desperate atmosphere. An informant explains further:

“I don't find it a very positive subreddit. At first, I did but sadly most of the posts are people desperate for any sort of relief, or have found no relief from non-drug therapies, so honestly besides realising I'm not alone...it's actually a forum that makes me feel more hopeless.” (Reddit08).

4.3.3 Effects of the Reddit SMT environment on appropriation for chronic illness management

Key informants suggested that each subreddit had its own culture and acted as “hive-minds” suggesting that Reddit is a composition of various virtual rooms composed of like-minded participants. The term hive-mind refers to a group mentality characterized by uncritical conformity and loss of a sense of individuality or personal accountability. In addition, the Reddit website seemed to act as a virtual meeting spaces where users could move from subreddit to subreddit based on their interest. These subreddits have its own set of moderators who set up and enforce rules for the subreddit. For example, the fibromyalgia subreddit has 6 moderators who created rules regarding spamming, trolling, diagnosis and politeness. At the time of data collection, there were 5,697 subscribers to the fibromyalgia subreddit. The environment theme is further sub-divided into two themes: 1) Technology features; and 2) Community.

1. Technology features

Reddit is designed to look like a discussion board so that the focus of the community stays on content and debate. Also, the design of the site is mostly text-based, according to key informants, this allowed them to be less distracted and more able to thoughtfully interact with others. Key informants suggested that they derived a sense of comfort from and familiarity with text-based communication. An informant explains: “I think because the features feel casual I don’t feel pressured in any way” (Reddit03). When asked to explain further, they indicated that they did not experience any feelings of pressure to immediately respond to content and they had the opportunity to consider their contributions/posts because the site has a confirmation page and so does not immediately submit any posts made by the users.
An informant explains the influence of the technology features further:

“As it's post(text) based rather than instant messaging style, it gives you the chance to really think about what you are going to type. Thanks to the lack of the Facebook or WhatsApp style tickers which let you know when someone has seen your message, you feel a lot less rushed and only comment if you actually think you have something to offer, support or otherwise” (Reddit07).

Overall, two main sub-themes were identified based on the technology features which provided these key informants with anonymity and a customized presence on the site as a result of the technology features of Reddit.

i. **Anonymity through Reddit profiles:** It was observed that Reddit by design allowed informants to operate anonymously on the site through accounts which may not be linked to any immediately identifiable details from users like email addresses or any other digital footprint. For these key informants, this was clearly beneficial to them and appeared to encourage their use of Reddit for illness management as one key informant explained:

“Well, it's nice to have anonymous support. It's weird, because I feel less bothersome with the anonymity” (Reddit06).

This perspective was echoed by most key informants who were able to interact on the site without fear of discovery by others in their real-lives or on the site.

ii. **Customized presence and user flairs:** It was observed that the fibromyalgia subreddit allowed users to customize their presence or post through custom taglines called “flairs” which could be customized from one subreddit to another. Also, posts to the subreddit could also be customized in a similar way to add additional information about the poster or the content. Figure 4.3 below provides an example from the fibromyalgia subreddit. The highlighted section demonstrates both types of flair: post and user.
2. **Community of understanding others**

Some informants (5) shared that fibromyalgia Reddit community had a solution-focused atmosphere, which they preferred because was more beneficial to them for illness management: “*r/fibromyalgia is less whingy and more about help and questions*” (Reddit08). Additionally, informants reported that the r/fibromyalgia community conducted through Reddit was a safe space to help others or discuss without many negative interactions or shaming. An informant explains:

“It's actually one of the very few subreddits where I've never seen negative interactions, shaming and the like - when people disagree, they actually discuss it rather than just arguing. I think it's because in the grand scheme of things it's a very small subreddit and as it's to do with health, people within are trying to keep it a safe, friendly place” (Reddit08)

i. **Gender relations and r/fibromyalgia as a feminine space:** One informant shared that there were sometimes requests from members to change that graphics of the subreddit to something more gender-neutral. The majority of informants reported that fibromyalgia is typically a women’s disease, although they are welcoming to anyone with the diagnosis:

“I have seen is a lot of people giving support to a male subscriber who worked with his hands (physical labour) and lost his job. A lot of us followed his story because fibro is usually women, and I think it's even harder for guys because 1) it's only like 10% of men who have the condition, and 2) to lose energy and be unable to do... physical labour... can take a hit on your masculinity... especially if you were super active before” (Reddit04).

She compares this with another related incident:
“One time there was a really weird fight about how the Fibro page was too "feminine". Lol. With the butterflies and stuff. And we listened. We did. But were kind of like.... "really?" I feel like, yeah, it's painful to be "emasculated" because of that condition, and then be reminded by purple colours and a girl in the corner. But like, no one goes on.... say, "woodworking" and tells you to make it more "feminine" to include women. Like basically it came down to feminine /= bad. He asked to change the pic. I would have changed the pic, probably. No one did, haha.” (Reddit04)

ii. **Subreddits as separate rooms and cultures:** Given the heterogeneity of Reddit, informants reported that they tended to treat each subreddit as a separate room with their own culture and norms. An informant explains:

“Yes it does have to do with the features, in particular the division of particular communities into subs...” (Reddit03).

This view is echoed by another informant who explains:

“On the site I tend to treat (each) subreddits as hiveminds of their own” (Reddit07).

### 4.3.4 Summary of findings

This section outlines the key themes that were found in the Reddit case study.

- Process of appropriating Reddit for chronic illness management
  - Lurking and daily participation on Reddit
  - Commenting and upvoting to show support
  - Subscription to multiple subreddits
  - Customizing experience of Reddit through community-built plugins and apps
  - Borderless appropriation of SMTs for illness management

- Individual incentives for adoption and continued use of Reddit for chronic illness management
  - Information support exchanges
    - Collective sensemaking
    - Illness advocacy
Chapter 4: The Reddit case study

- Emotional support exchanges
  - Dealing with illness stigma
  - Compartmentalizing fibromyalgia from real life
  - Online friendships and social support
  - Discrepant emotional support exchanges

- Effects of the Reddit SMT environment on appropriation for chronic illness management
  - Technology features
    - Anonymity through Reddit profiles
    - Customized presence and user flairs
  - Community of understanding others
    - Gender relations and r/fibromyalgia as a feminine space
    - Subreddits as separate rooms and cultures

The next section provides a discussion of key findings from the Reddit study and outlines the identified affordances from this case.

4.4 DISCUSSION

In this section, findings from this case study are analysed. A deeper discussion in relation to the practice lens and existing studies is provided in Chapter 9.

Process of appropriating Reddit for illness management

Concerning the process of appropriation of Reddit, findings clearly show that these informants practiced lurking frequently to remain connected to others in the community and stay aware of any information posted on the subreddit. Lurking allowed passive consumption of content posted by others on the site without pressure to interact. Moreover, in the Reddit case, commenting and upvoting seemed to be applied as a way to show support to others in the community and ensure the visibility of new posts.

Because the design of Reddit is simplistic (like an online bulletin board) key informants also shared that they sometimes augmented the functionality of Reddit through browser plugins. These plugins helped customize Reddit and made it easier to
use, which is in line with previous studies that suggest workarounds are an effort by users to fit a technology to their needs (Davis 1989; Mendoza et al. 2010). Findings also suggest that informants practiced adaptive appropriation by using the separate subreddits in Reddit SMT to fulfil different needs such as entertainment, gaming and chronic illness management purposes.

Finally, key informants were observed to engage in the complementary borderless appropriation of multiple SMTs to serve different aspects of illness management. These key informants reported having multiple SMT accounts across a range of technologies including: Tumblr.com, MDjunction.com, patientslikeme.com in addition to their Reddit SMT account they had for the case study to maximise the support and information they received about fibromyalgia.

**Influences on appropriation of Reddit for illness management**

Findings from this case study suggest that these chronically ill individuals adopted Reddit due to challenges involved in the experience of fibromyalgia such as stigma and low offline support. These individuals were incentivized to adopt and use Reddit along two main dimensions: for information support exchanges and to gain emotional support. Findings in this case study also suggest that through appropriation of Reddit, key informants were able to gain access to a community of similar others who shared information that aided their illness management practices. Further, because of these exchanges; key informants were also able to advocate for themselves with their healthcare providers and achieve better outcomes. This is in line with previous research which suggested that SMT appropriation could lead to patient advocacy and empowerment (Househ et al. 2014; Rozenblum and Bates 2013). In addition, findings indicate that through these information exchanges, key informants with less access to care were able to crowd-source illness and medication-related information. Therefore, adoption and continued use of Reddit SMT helped to reduce the disparity in care provision for its users who were in less favourable geographical locations such as Japan (Agarwal et al. 2010; Goh et al. 2016).

Further, findings show that emotional support served to help these informants to cope with the stigma involved in the experience of an invisible illness like fibromyalgia. there were discrepant emotional support exchanges. Unlike previous studies, social support was identified as a sub-component of emotional support because its purpose was to gratify needs that arose from the isolation that results from an
invisible chronic illness. There were mixed perceptions of the value of social support due to trust issues and wanting illness management practices to remain compartmentalized from their normal life. While some informants were able and willing to develop friendships with other members they had encountered through the SMT, key informants preferred to interact only through the SMT. One key informant had shared that because of the age difference between her and other members of Reddit, she didn’t form any close friendships with others even on the subreddit.

Findings support the notion of Reddit SMT acting as a source of structure for these individuals as they could organize themselves into a community with roles, rules and norms (Orlikowski 2000; Schmitz et al. 2016). The features of Reddit also supported these cohorts’ efforts to compartmentalize their illness-related activities from their other actions on Reddit SMT through the provision of features like throw-away accounts and subreddits. Other significant findings related to Reddit SMT concerned the customization of online presence through features like flairs.

The next section provides outlines various affordances identified by the researcher during the case study.

*Identified affordances which enable or disrupt positive illness outcomes*

Because of the interactions between the individual incentives to adopt and use Reddit for illness management and the influences exerted on these cohorts by the community and technology of the Reddit site, the following eight key affordances which served to enable illness management were observed.

- **Belonging:** Reddit affords these cohorts the ability to belong in a community of others who are connected by a shared condition, as a consequence of the community provided by the SMT, these cohorts are able to feel connected to others in the community through sharing experiences or subscribing to the subreddit.

- **Compartmentalization:** This affordance allowed key informants to operate in each subreddit as a separate space, with the option of customizing taglines, making use of throw-away accounts and other options which enabled separation of their activities on Reddit SMT.

- **Considered Participation:** The text-based nature of Reddit allowed thoughtful communication by chronically ill individuals. Key informants
indicated that they appreciated the lack of immediacy that the text-based nature of Reddit provided.

- **Storytelling:** Chronically ill cohorts could share their stories with others in the Reddit SMT through the posting feature provided by the tool. Through posting, key informants could narrate their experiences and share with others in the same community.

- **Presence:** The Reddit SMT provided a sticker on the side of the subreddit which indicated how many members of the community were online at any time.

- **Reputation:** Reddit affords this through a point system called karma which is allocated to the user as a result of his/her posts and comments on the platform. Karma is finally determined by the community through the number of likes they give to a specific post.

- **Sensemaking:** The sensemaking affordance refers to the extent to which the user is able to utilize the tool in making sense of their symptoms through collaborating with others or reading the experiences of others. This affordance may be realized before or after the official medical diagnosis by healthcare professionals. Through activities like lurking or participating in these subreddits, these informants could learn about their illness and collectively make sense of symptoms and problems presented to the community.

Additionally, there was a key constraint which acted as a disruptor which was:

- **Emotional overload:** Due to the constant deluge of notifications and updates of members posts on the group feed, this served as a constraint. Some key informants noted the emotional overload they experienced as a consequence of participation on Reddit.

The next chapter presents findings from the YouTube case study.
Chapter 5: The YouTube case study

Illustrative quote: “I was crying, explaining my frustration, the pain. It was long... felt like forever before I could get a diagnosis. But I know I was lucky because people go about their lives for years before being diagnosed. This is why I created my YouTube channel” (YouTuber03).

INTRODUCTION

The previous chapter (Chapter 4) presented the findings from the case study with mixed methods of chronically ill adults on Reddit SMT. Similarly, this chapter presents the findings from the YouTube case study to address the guiding research question for this thesis: How do chronically ill adults engage with and appropriate social media tools to better understand and manage their illness? The chapter proceeds with Section 5.1 which describes the background and relevant history of YouTube SMT; Next, Section 5.2 outlines the data collection strategy for this case including an overview of the key informants and their antecedent experiences to appropriation of YouTube. Subsequently, Section 5.3 presents key findings from the case study. These findings are demarcated into three aggregate dimensions: 1) process of appropriating YouTube for illness management; 2) individual incentives for adoption and use of YouTube; 3) effects of the YouTube environment on appropriation for chronic illness management. The chapter concludes with a discussion in Section 5.4 and outlines affordances which act to enable or disrupt the process of appropriation of YouTube for chronic illness.

5.1 CONTEXT OF THE CASE

5.1.1 The YouTube social media tool: A brief background

YouTube is a video-sharing social media tool that was developed by Chad Hurley, Steve Chen and Jawed Karim in 2005 while they were employees of the PayPal Company (Fitzpatrick 2010). Since its inception, YouTube has been one of the most active video-sharing sites and has spawned billions of user-generated videos.

4 Some findings from this chapter were accepted for publication and presentation at the 27th European Conference on Information Systems (ECIS) in Stockholm, Sweden.
which have facilitated the creation of ad-hoc content-centred communities (Dallas et al. 2012; Konijn et al. 2013). Table 5.1 below lists key features of YouTube.

<table>
<thead>
<tr>
<th>Feature</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>User account</td>
<td>A user account is required to create videos, comment/like/favourite videos on the YouTube SMT. An account is linked to the individual and their other associated Google services</td>
</tr>
<tr>
<td>Channel</td>
<td>A channel refers to a profile that has uploaded video content and belongs to an account. A user may have multiple channels associated with their account.</td>
</tr>
<tr>
<td>Activity feed</td>
<td>A news feed keeps the user updated on the actions of each of the other members of the user’s network.</td>
</tr>
<tr>
<td>Recommended content</td>
<td>This feature generates a list of videos that might interest the user which have been curated and suggested based on the user’s activities on YouTube. For instance, the recommended content feature generates related health videos after a user has viewed a video about health and fitness.</td>
</tr>
<tr>
<td>Video publication</td>
<td>This feature allows users to publish and edit videos that are visible to 1-n members of their selected network depending on each privacy settings attached to the video by its uploader.</td>
</tr>
<tr>
<td>Live streaming</td>
<td>This feature allows the user to create and stream videos live to their subscribers or anyone on the site</td>
</tr>
<tr>
<td>Creator studio</td>
<td>The creator studio allows users to manage their channel by providing tools which allow: organization of videos, moderation of comments, viewing analytics information for each video and the channel in general and access to the audio library provided by YouTube.</td>
</tr>
<tr>
<td>Content embedding</td>
<td>This feature uses the social plugin provided by YouTube to allow videos posted on the site to be shared and embedded on external sites.</td>
</tr>
<tr>
<td>Comments</td>
<td>Commenting allows logged in users on the site to communicate with each other and with the YouTube under an uploaded, published video. This feature may be enabled or disabled by the uploader of the content.</td>
</tr>
<tr>
<td>Hash-tagging</td>
<td>Hash-tags are special keywords which may be added to a video upload by the YouTuber and enables categorization of the video based on its topic. This also enables the search function on YouTube to return videos with similar hashtags when that hashtag link is clicked on by the user.</td>
</tr>
<tr>
<td>Search</td>
<td>The search function returns videos related to the search query input from a user.</td>
</tr>
<tr>
<td>Monetization</td>
<td>Monetization on YouTube allows YouTubers to earn money from advertising placements on their video uploads. To be eligible for monetization, an account must: 1) agree to the YouTube partnership terms and conditions; 2) have at least 4,000 watch hours over the last 12 months and; 3) have at least 1,000 subscribers.</td>
</tr>
</tbody>
</table>
Any user with a YouTube account who has access to a recording device and an Internet-connected computer may become a YouTuber if they upload video content to the website (Dallas et al. 2012; Fitzpatrick 2010; Gray 2014). Consequently, YouTube has launched numerous initiatives to make the process of content creation easier to manage and to incentivize content creation, for instance: the creator studio feature which allows users to edit and monetize uploaded videos in compliance with the copyright guidelines set out by the site (Rosenbaum 2012; Wasserman 2015).

Some of the key features that YouTube provides include: video publications; user account/channel; subscriptions; content recommendation; hash-tagging; comments; private messaging and; a creator studio. The landing page of YouTube provides a curated list of the most popular videos of the day based on the site’s popularity selection algorithm and one is free to view videos without the need to log in (see Figure 5.1, below).

![YouTube landing page](image)

Figure 5.1: YouTube landing page

YouTube is available online as: a web version for desktop, as well as iOS, Android OS and Windows phone applications. In addition, YouTube provides an API endpoint for developers through the Google developer console suite for external service integrations. In addition, videos uploaded are generally free to view for anyone who has Internet access, although there are options to make a video unlisted or private. Uploading an unlisted video causes it to not be displayed in site search results; only others who have the universal resource link (URL) of that video item can view it. Private videos are only available to other users who are sent invitations to view them.
from the uploader of the video. Additionally, access is restricted to those who are logged in with YouTube accounts.

5.1.2 Being chronically ill on YouTube

YouTube serves as a social media tool containing videos posted by users of the site, commonly denoted as YouTubers. YouTubers create and upload videos on a variety of topics such as: fashion, beauty, religion, gaming, pets, documentaries and others which are largely categorized by the site into categories such as: Auto & Vehicles, Beauty and Fashion, Comedy, Education, Entertainment and so on. In addition, there are several chronically ill users who make uploads to share their experiences with managing their illness, as well as sharing their day-to-day lives with others who may have the same illness. Further, these uploads also attract other users to view, comment and interact with the chronically ill YouTuber, these interactions occur in the comment section of their uploaded videos.

The key informants for the semi-structured interview are Video bloggers (contracted to “Vloggers”), also known as YouTubers, which is the term that will be used for the remainder of this chapter. Similarly, their audience will be referred to as “commenters” for the remainder of the chapter. Commenters were not interviewed, but their comments on these videos were also observed to obtain a holistic picture of appropriation of YouTube by chronically ill cohorts.

All key informants reported that they had spent several years suffering from fibromyalgia before they obtained a diagnosis. They also shared that from their experiences there were no specific diagnostic tests for fibromyalgia, diagnosis for them was through a process of elimination which spanned several years for these cohorts. A key informant explains:

“I had been seeing the same doctor for nearly 20 years at that point, so we had built a trust up between us. Most people go back and forth with their doctors for months or years, but she and I had already been doing the whole "process of elimination". She still ran some tests just to be sure nothing had changed, but in the end, it was really the only thing left that explained why I was feeling the way I do” (YouTuber06).

YouTuber is a term that is used to denote YouTube users who share and appear in videos on the site.
Another informant confirms, sharing her frustrations at not having any tests that could simplify her process of diagnosis, she said:

“I started researching on my own …the things I was feeling. Because doctors gave me no answers and I knew things were not right, but all blood tests came back normal” (YouTuber05).

The next section discusses the data collection and analysis procedures that were applied to the YouTube case study.

5.2 DATA COLLECTION AND ANALYSIS

Qualitative data collection commenced through a search using on YouTube with the keywords of “fibromyalgia” and “fibro” to identify uploaded videos containing those keywords using the criteria specified in the previous chapter on the units of analysis for the case studies (Section 3.4.1). Next, the researcher carefully examined the profile information of the uploader, selecting only channels confirming that the YouTuber has fibromyalgia. Subsequently, messages were sent using both the YouTube chat feature or through social media contact details posted on the channel information page. The introductory messages sent to solicit informants for the study contained an opening message, in the form of a plain language statement describing the project, its aim; the expected activities that would be required from participants and contained copies of the consent form (see Appendix B).

In total, 40 messages were sent to YouTubers, soliciting their participation in the study and 13 individuals responded; some (3 out of the 13), were unable to schedule a suitable time because of their illness; 1 user was excluded due to ethical concerns related to her age as she was younger than 18 at the time of data collection, while 9 users confirmed that they had been diagnosed with fibromyalgia agreed to participate in the semi-structured interviews. The researcher also observed some videos posted by key informants and their interactions with commenters to better understand how YouTube was appropriated during illness management practices of adults with fibromyalgia. Table 5.2 below outlines the demographic information of the key informants who participated in the semi-structured interviews. As stated in Chapter 3,

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6 The minimal risk ethics criteria states that study informants should be 18 and older to participate in the study.
Section 3.5.1, the interview questions were focused on issues pertaining to appropriation, which included: individual reasons to adopt and use YouTube SMT, the influence of YouTube on their personal chronic illness practices, the process of appropriating YouTube; effects of the environment provided by YouTube on appropriation etc.

<table>
<thead>
<tr>
<th>Key informant</th>
<th>Gender</th>
<th>Age Group</th>
<th>Location</th>
<th>Reported level of self-efficacy with illness</th>
<th>Join date</th>
<th>First upload</th>
<th>Overall view count for channel</th>
</tr>
</thead>
<tbody>
<tr>
<td>YouTuber01</td>
<td>Female</td>
<td>30-35</td>
<td>Spain</td>
<td>Experienced</td>
<td>13-3-2016</td>
<td>13-03-2016</td>
<td>11,911</td>
</tr>
<tr>
<td>YouTuber02</td>
<td>Female</td>
<td>30-35</td>
<td>Canada</td>
<td>Experienced</td>
<td>24-11-2014</td>
<td>13-12-2014</td>
<td>217,282</td>
</tr>
<tr>
<td>YouTuber03</td>
<td>Female</td>
<td>20-25</td>
<td>United States</td>
<td>Transitioning patient</td>
<td>2-03-2015</td>
<td>5-02-2016</td>
<td>52,402</td>
</tr>
<tr>
<td>YouTuber04</td>
<td>Male</td>
<td>20-25</td>
<td>United States</td>
<td>Transitioning patient</td>
<td>4-06-2013</td>
<td>28-6-2016</td>
<td>2,419</td>
</tr>
<tr>
<td>YouTuber05</td>
<td>Female</td>
<td>20-25</td>
<td>United States</td>
<td>Newly diagnosed</td>
<td>19-11-2016</td>
<td>19-11-2016</td>
<td>25,982</td>
</tr>
<tr>
<td>YouTuber06</td>
<td>Female</td>
<td>35-40</td>
<td>United States</td>
<td>Newly diagnosed</td>
<td>4-8-2011</td>
<td>1-04-2016</td>
<td>63,125</td>
</tr>
<tr>
<td>YouTuber07</td>
<td>Female</td>
<td>40-45</td>
<td>United States</td>
<td>Experienced</td>
<td>19-2-2017</td>
<td>19-2-2017</td>
<td>1,957</td>
</tr>
<tr>
<td>YouTuber08</td>
<td>Female</td>
<td>40-45</td>
<td>United States</td>
<td>Experienced</td>
<td>24-9-2012</td>
<td>5-3-2018</td>
<td>10,529</td>
</tr>
<tr>
<td>YouTuber09</td>
<td>Female</td>
<td>30-35</td>
<td>United States</td>
<td>Experienced</td>
<td>14-12-2017</td>
<td>2-1-2018</td>
<td>976</td>
</tr>
</tbody>
</table>

Additionally, key informants were asked to classify themselves based on how long they had been diagnosed with fibromyalgia and their self-reported efficacy in managing the illness, the three categories for YouTube informants were: newly
diagnosed, transitioning, and experienced (Refer to Chapter 3, Section 3.7.1 for clarification of these terms).

For the quantitative portion of data collection; the researcher made use of Netvizz tools and conducted a search using the terms: “fibromyalgia” and “fibro” following the data collection protocol outlined in Chapter 3, Section 3.5.2 (Rieder 2013). This search query returned a Comma Separated Values (CSV) file containing data about videos that matched the keywords and the data contained in this flat file included video category, description, title and interaction metrics (likes, dislikes, views etc). Next, the researcher conducted data cleaning to remove duplicate items, entries that were not in English and entries that were not about fibromyalgia.

As discussed in Chapter 3, Section 3.5.4, analysis was restricted to textual content in the descriptions of the submitted videos and associated comments to ensure compatibility with the data analytics methods used for the study (See Chapter 3, Section 3.7.4). The following section presents the findings from the case study of YouTube SMT.

5.3 FINDINGS

The findings from the YouTube case study are demarcated under three broad categories: 1) process of appropriating YouTube; 2) individual incentives for adoption and continued use of YouTube and; 3) effects of the YouTube environment on appropriation.

5.3.1 Process of appropriating YouTube for illness management

From the descriptive statistics of the text corpus of YouTube, it appears that the most common activity on YouTube site is viewing/watching content. The range of values for views of entries in the dataset is from 0 views to 184831 views for video entries, as illustrated in Table 5.3 below.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Count</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Min</th>
<th>25%</th>
<th>50%</th>
<th>75%</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Views</td>
<td>700</td>
<td>2214.42</td>
<td>11132.85</td>
<td>0</td>
<td>46.75</td>
<td>168</td>
<td>707.5</td>
<td>184,831</td>
</tr>
<tr>
<td>Comments</td>
<td>700</td>
<td>12.03</td>
<td>43.01</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>527</td>
</tr>
<tr>
<td>Dislikes</td>
<td>700</td>
<td>1.71</td>
<td>9.26</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>157</td>
</tr>
<tr>
<td>Favourites</td>
<td>700</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Likes</td>
<td>700</td>
<td>38.33</td>
<td>166.54</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>16</td>
<td>2,751</td>
</tr>
</tbody>
</table>
Data from the text corpus showed interaction metrics for videos such as number of views, comments, dislikes and favourites. It seems that at its core, YouTube is comprised of a group of vloggers who create content and share with peers, but a significant majority of users are viewers who may or may not have accounts on the site, the next level of users is those who actively engage with the content posted through liking, disliking and commenting, within that group are the subscribers to a channel. It appears that all key informants started their appropriation journey through viewing and then transitioned to vlogging over time. Moreover, some key informants (7 out of 9) shared that they made the effort to log in to YouTube daily because they wanted to interact with commenters, monitor performance of their videos, and related activities on the site. One informant explains:

“It really sort of depends on the week as my depression can really change how much I interact but I try to get on there at least once a day and respond to comments or watch someone else videos - on a really good day I will respond to as many as many 5 or 6 videos and 5 to 10 comments on my own videos - on bad days though I will only ever look around and maybe click on random content but not interact at all... when thinking about how often I have bad days (approximately 3 or 4 times a week)” (YouTuber02).

It was suggested by most (7 of 9) study informants that part of this was because they wanted to adhere to a schedule for uploading videos to YouTube:

“I am on YouTube every day and am recording every day” (YouTuber04).

However, one informant shared:

“My day doesn't tend to include YouTube generally! Once a week I spend 15 minutes or so filming a video, then 30 uploading making the image and sharing” (YouTuber07).

To explore appropriation processes further in this context, the qualitative themes below provide more insight on the intricacies of appropriation for these cohorts. The following section outlines the three themes that were identified during analysis concerning appropriation process of YouTube which are: 1) viewing to vlogging; 2) building workarounds for YouTube features and; 3) borderless appropriation of YouTube as part of a toolkit. These themes are presented below:
1. **Viewing to vlogging**

On average, the study informants had 1.6 years between creating accounts and making their first video uploads. This range varied significantly, with YouTuber01 creating an account and making her first upload on the same day while YouTuber08 had 6 years between the initial account creation and creating her first video upload. The majority (8 of 9) of the study informants shared that they had joined YouTube several years as viewers and commenters before becoming vloggers. An informant explains this stating:

“I joined YouTube as a platform in 2010, but I only started participating as a viewer/commenter probably around 2014.” (YouTuber06).

All informants shared that their diagnosis had motivated them to start creating and uploading video content to YouTube to share their own experiences with fibromyalgia. One informant explains:

“I had watched YouTube videos for many years and always enjoyed the Vlogger community. A university flatmate introduced me to the platform in 2007. I joined YouTube as I wanted to voice my own opinions and experiences in dealing with chronic health issues” (YouTuber03).

2. **Building workarounds for YouTube features**

For each of these key informants, it was clear that they faced some difficulties in employing YouTube features to YouTubing related tasks like editing video content or communicating with others on the site. To bypass these challenges, it was observed that additional technologies ranged from free software to more expensive professional video editing tools were applied to carry out those tasks. Some informants (6 out of 9) reported that they used tools such as video editing software, phone or video cameras, tripods to carry out their process of video creation. An Informant explains:

“I use Sony Vegas pro to edit all my videos, YouTube editing sucks. I record my videos at 60fps and 1080p 32mbps which is a lot for YouTube but with Sony Vegas I can do what I want” (YouTuber04).

For some other informants, they used basic tools like their mobile phones or laptop cameras to create content as another informant shares:
“To start out I had my iPhone, and that was it and I started editing on iMovie. Because I can no longer work, I couldn't afford to buy a bunch of equipment. I was just given a refurbished MacBook Air and so now I am using that, and I have invested in some better software for editing my videos” (YouTuber08).

3. **Borderless appropriation of YouTube as part of a toolkit**

Given that a primary capability of YouTube involves presentation of the self to the wider community, it was observed that key informants also adopt a suite of other social media tools. It was clear that these individuals sought to expand their reach and promote their content across various social media. One informant explains:

“Social media is a great way of sharing your story across platforms. I've found some YouTubers through Twitter or Instagram. Someone might stumble on a tweet of mine and follow the link there back to my channel. So it helps promote your channel to a wider audience than those already on YouTube” (YouTuber06).

It was also evident that cross-platform promotion of content was seen as essential by these cohorts because it could serve as a way to drive up subscriptions and view counts which would impact monetization. In line with this concept, these cohorts maintain the same profile name across social media sites to increase their visibility and maintain brand consistency:

“Indeed, they (my other social media accounts) are all meant for supplementing my main channel and reaching my audience in different ways. I've just noticed some things are more easily shared on some medias, rather than others - so hence why I share different stuff in different places. And I started the YouNow.com account from being inspired by another, bigger YouTuber (Stef Sanjati) because I noticed it was a really nice way to connect on a more personal level with your audience” (YouTuber02).

It was also suggested from the interviews that an additional reason for this was due to the glitchy nature of YouTube features:

“The YouTube subscription box system is notoriously glitchy. Videos get delayed or don't make it into sub boxes at all. People get unsubscribed from

__________________________________________

7 https://www.younow.com/
channels without knowing. So, giving people a way to follow me outside of YouTube is just a good idea in general” (YouTuber06).

5.3.2 Individual incentives for adoption and continued use of YouTube for chronic illness management

First, the YouTube text corpus was explored to characterize its content using a word cloud to assess the main topics that occurred in the collected content as illustrated in the word cloud in Figure 5.2 below. The most frequently occurring words in the dataset are related to promoting videos and contain keywords about fibromyalgia symptoms such as pain. The word cloud indicated that the most frequently occurring words in the dataset were: pain, video, symptom, help etc. These terms indicate that the collected text were discussions about these cohorts’ experience of fibromyalgia. In addition, the terms Twitter and Facebook also appear frequently in this corpus indicating that these cohorts may be inviting their peers to connect with them through other social media tools or engaging in cross-promotion of their YouTube videos through these other social media tools.

Figure 5.2 Word cloud illustrating the most frequently appearing words in the YouTube dataset

In addition, the researcher conducted topic modelling using LDA to extract more meaningful topic clusters. This LDA extracted the 50 most salient topics from the text corpus which were represented through 10 terms per topic, from which 5 core themes were interpreted based on the analysis method described (see Chapter 3, Section 3.5.4).
These identified themes from are illustrated in Table 5.4 below and were about: information giving (58%); seeking donations (22%); invitations to connect on other social media tools (8%); identifying with others (6%); soliciting community formation (4%) and; offering to share emotional validation (2%).

Because topic modelling only provides a high-level understanding of the individual incentives to adopt and continually use YouTube by these cohorts, it was important to gain deeper insights from the qualitative aspect of the study.

<table>
<thead>
<tr>
<th>Themes/Definition</th>
<th>Sample sentence from the YouTube text corpus</th>
<th>Sample topic group from LDA</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information giving:</strong> refers to topic clusters that are about giving or receiving information about illness</td>
<td>“Hi guys and welcome to my third Fibromyalgia video! In this one I discuss some of the common symptoms of Fibromyalgia that I suffer with and share a few of my tips on how to deal with them.</td>
<td>cancer author sharing video experience process illness disease day fibromyalgia</td>
<td>58</td>
</tr>
<tr>
<td><strong>Seeking donations from others:</strong> Denotes topic clusters concerned with obtaining or giving monetary or similar resources</td>
<td>Just a friendly video - To keep the videos coming – contribute at <a href="https://www.gofundme.com/removed">https://www.gofundme.com/removed</a> and also my brother, at <a href="https://www.gofundme.com/removed">https://www.gofundme.com/removed</a></td>
<td>amazon ref email book osteoporosis question revolution utf keywords qid</td>
<td>22</td>
</tr>
<tr>
<td><strong>Invitations to connect on other social media tools:</strong> refers to topic clusters that discuss other social media sites or the specific action or features of YouTube</td>
<td>Sorry the lighting sucks, that’s what happens when you film at night Come be my friend on: Facebook, Twitter, Instagram, Pinterest</td>
<td>Twitter Instagram Facebook Painfreekitchen Pinterest Day Tumblr Laser Fibromyalgia Video</td>
<td>8</td>
</tr>
<tr>
<td><strong>Identifying with others:</strong> refers to topic clusters that are concerned with crafting an identity using terms common in the fibromyalgia community such as: warrior, spoonie or fibomite</td>
<td>This video is for all the Fibro Warriors &amp; Fibro Girls or for anyone whose family-member/friends suffer from Fibromyalgia</td>
<td>pinkbeautyfox warrior maybe fibro patient going news YouTuber positive came</td>
<td>6</td>
</tr>
<tr>
<td><strong>Soliciting community formation:</strong> represents topic clusters that are concerned with soliciting or offering community formation or interactions</td>
<td>Being diagnosed with Fibromyalgia is frustrating because there is not a whole lot of information or research available. I may have Fibromyalgia, but the diagnosis does not have me! I will fight this and find a way to live the life I used to. I would love to have you subscribe to my channel to help grow this community of people who are seeking out the Lord. Some videos are strictly faith based while others are just plain silly and fun. I hope you jump on board this journey and we can learn from each other!</td>
<td>wholeness community venture max test YouTube fibromyalgia join healing chair</td>
<td>4</td>
</tr>
<tr>
<td><strong>Offering to share emotional validation:</strong> represents topic clusters concerned with the exchange of empathy, caring or encouragement</td>
<td>My husband and I, spent over 6 years writing the story of my life with Fibromyalgia. It was hard not only talking about my battle with this insidious disease, but talking about our personal life which it affected greatly. I would love for my story to make a difference in your life so that you</td>
<td>injury husband video variety life fibro vlogs walk film talking</td>
<td>2</td>
</tr>
</tbody>
</table>
The following section unpacks the four corresponding overarching qualitative themes (each with its own sub-themes) are outlined below, demarcated as: information support exchanges and emotional support.

1. **Information support exchanges: Making sense of fibromyalgia and raising awareness**

   Another theme that was induced from the observations and semi-structured interviews was that these key informants, engaged in information support exchanges with similar others (both other YouTubers and their commenters). All key informants stated that they had gained knowledge about their symptoms and learned coping strategies through interaction with other users on YouTube. Informants also shared that the process of managing fibromyalgia was challenging because there was “no one size fits all” solution for managing symptoms:

   “Not one of us is exactly like the other. There are overlapping similarities, but even our med tolerances are vastly different. What works for one of us, may or may not work for the other. I try to stress that with everyone, as well as reminding them about talking to their Dr, before trying some new med/herb/gadget, etc.”
   (YouTuber09)

   When asked if and how they used information obtained from YouTube, some (5 of 9) informants indicated that they obtained information about how to cope and one informant explained:

   “Through just random vlogs, videos and interactions with various other people on YouTube I’ve learned a lot about coping and working on my mental health.”
   (YouTuber04).

   It appeared after these cohorts create their channels on YouTube, they remain consumers of health-related videos on YouTube so that they can stay informed on the latest research and the coping practices of others with the same illness. An informant explains:

   “YouTube content is very beneficial for me in that I can research meditation, find meditation music, I can research products that may help with pain management. It has been great for me so that I can arm myself with as much knowledge as possible”
   (YouTuber08).
Also, the majority of key informants (8 out of 9) indicated that this was a key incentive for them, to share their experiences with the community. One informant expressed it this way:

“I had watched YouTube videos for many years and always enjoyed the Vlogger community. I joined YouTube as I wanted to voice my own opinions and experiences in dealing with chronic health issue” (YouTuber03).

These exchanges were observed to be reciprocal between the YouTubers and their commenters as illustrated by a comment left on one video by YouTuber02 about the side effects of Lyrica:

“I tried Lyrica and it made me very sick. Something in Lyrica does not agree with me!!! I don't do well with chemicals. I use Promethazine & Effexor. It also helps me with the nausea from pain & IBS. To be honest, there really is no real quick fix without side effects! To me sadly enduring seems to be the only real fix........don't mean to be a downer! Love you” (a commenter).

The information support theme is comprised of the following 3 subthemes which are i) collective sensemaking to learn about coping with fibromyalgia; ii) applying shared coping mechanisms and; iii) illness advocacy. These themes are presented in the following section:

i. Collective sensemaking to learn to cope with fibromyalgia: It was observed that through interactions with other YouTubers, informants could self-diagnose their chronic illness in collaboration with their peers on YouTube. Once they had sufficient information, they took evidence to their general practitioner or rheumatologists to help them in receiving a definitive diagnosis or to clarify the cause of fibromyalgia-related symptoms. One of the key informants confirms this observation by sharing her experience:

“I spent a few months watching a YouTuber (fibro-vlogger) who had done some videos on her condition and living with a chronic illness. I related to a lot of what they were saying and looked up both fibro and M.E. on the Mayo Clinic's website, just to see on a basic level what the symptoms were and they both matched perfectly. That was when I went to see my doctor. And it's funny, because I also expected her to say, no, that's not it, all your tests are normal and you're fine, but
instead she agreed that fibromyalgia is the most likely thing that we were dealing with” (YouTuber06).

ii. Applying shared coping mechanisms: It was also observed that apart from discussing major fibromyalgia symptoms, these informants also exchanged advice to help the management of secondary symptoms such as chronic fatigue and pain. Key informants confirmed the value of these coping strategies and shared that they regularly apply the tips and suggestions in videos from peers into their daily illness management practices, one informant elaborates on this, stating:

“Through just watching random vlogs (about fibromyalgia), videos and interactions with other people on YouTube I’ve learned a lot about coping with fibro in general and working on my mental health” (YouTuber02).

Among the therapies that were reportedly applied by the key informants because of suggestions on YouTube were: acupuncture, weighted blankets and other holistic strategies.

iii. Illness advocacy: A recurring issue that was discussed by these informants was the lack of understanding by their general practitioners concerning the ramifications of fibromyalgia. Therefore, YouTube channels and videos offer these cohorts the opportunity to create content that raises awareness about fibromyalgia with their physicians:

“I want to reach more Physicians who treat Fibromyalgia to implore them to do more research on Fibromyalgia, and not just go along with what exactly they learned in school. Clearly their way is not helping the Fibro community. I want Doctors to show more empathy to their patients who suffer and not dismiss how they feel.” (YouTuber08).

In the following excerpt, one of our informants discusses their motivation for increasing the public understanding of fibromyalgia and how they hope to help others through advocacy:

“I hope to spread information about fibromyalgia and my experience with it because it is an unknown disease” (YouTuber05).
2. Emotional support exchanges: YouTube as a safe space

All key informants explained that YouTube had generally provided them with positive emotional exchanges, as an informant explained:

“That's how this all began. The positive response I receive from a post about my Fibro experience. It was incredible and enlightening to see the love and support that poured out from that post. Hence why my channel was born. It gave people courage and hope. I was flooded with heartfelt responses!” (YouTuber09).

Additionally, key informants explained that they had varying degrees of support offline either from family members or romantic partners. Still, it was observed that YouTube gives them the opportunity to engage with others who understand what they are going through and gain additional support. Most (8 of 9) informants had very supportive family and friends, but one informant shared that his experience was different:

“Yes, some days are better than others but since I got sick, I haven't been the same sense and without my family willing to help me at all I feel alone and lost it be a lot worse if I lost my gf [girlfriend]” (YouTube04).

While there is also some negative and upsetting content on YouTube, some key informants (7 out of 9) shared that it serves as a good distraction from the day-to-day symptoms of fibromyalgia:

“For the most part it acts as a really good distraction from my pain and mental health issues; as well as a lot of good reminders to self-care and help myself get out of my depression [as] best I can - so mostly positive - but there have been times where I've come across very emotionally upsetting content, full of bigotry or hate and it can trigger some harder emotions” (YouTuber02).

Another informant confirms, sharing:

“I've received a few comments that left me wondering what the person's intention was, but they weren't horrible or rude comments, just kind of laughably confusing if that makes sense. I've only received one comment that I would consider a troll type of comment.” (YouTuber05).

Moreover, all 9 informants shared that they gained a sense of purpose, and a sense of accomplishment from their YouTubing practice as an informant explained:
“I generally really enjoy using YouTube. I am excited to read comments and respond. You achieve a sense of accomplishment by uploading content. In terms of negative emotions, sometimes you can feel self-conscious watching yourself back” (YouTuber03).

Emotional support seems to be enacted through different means as evident from the following 5 themes that emerged: i) fighting stigma and giving legitimacy to the "trash can disease"; ii) crafting an illness identity; iii) self-presentation as therapy; iv) building borderless relationships and; v) coping with the isolation of chronic illness.

i. Fighting stigma and giving legitimacy to the "trash can disease": A recurring theme shared by all key informants concerned giving legitimacy to the experience of having an invisible illness like fibromyalgia. Key informants shared that they aimed to help give visibility and legitimacy to their experiences of fibromyalgia. An informant shares:

“My vision is to make Fibro known in its entirety. No more stigmas of the "trash can disease", but real knowledge” (YouTuber09).

Another informant confirms and explains further:

“We are treated like drug addicts seeking our next high, when really all we want it the pain to stop. We want help. We want understanding, we want respect, we want our lives back! We want people who don’t have this illness to better understand what we go through every day” (YouTuber08).

ii. Crafting an illness identity: It was observed that all the key informants included some combination of the terms ‘spoonie; fibro fighters and; fibro warriors’ and others in their names or their channel descriptions on YouTube. Another way that these cohorts formed a more positive identity of their illness was through identifying which celebrities are rumoured to also suffer from fibromyalgia. Among the celebrities who often appear in these contexts are: Avril Lavigne (singer), Lady Gaga (singer) and Morgan Freeman (Actor). In fact, the concept of identity formation was so strong in one of my informants that she regularly dyed hair purple (the unofficial colour for fibromyalgia). When asked if this was just for the sake of the channel and what this physical change represented to her, she explains her broader intention and concept behind her ‘spoonie’ identity, saying:
“We have business cards, I generally keep my hair purple, knowing that people usually comment on it, so that opens up the dialog to discuss that my hair is purple for Fibro Awareness” (YouTube09).

iii. Self-presentation as therapy: On the YouTube site, there were observed to be two somewhat opposite sides of the coin in terms of self-presentation: There are YouTubers who create videos and through this action became a central part of the community and there are the viewers who may anonymously consume the produced content. Key informants confirmed the value of self-presentation to them, with one informant saying:

“Anyone who says they don't care at all if people watch is either lying or fooling themselves. If I didn't care if people watched, I'd stick to blogging or writing in a journal” (YouTuber06).

When prompted to explain further, these informants shared that they derived a sense of psychological relief, as an informant explains:

“I find posting to YouTube oddly therapeutic; I find there to be something very liberating about talking to the public on YouTube – like a better version of therapy!” (YouTuber03).

Because communication on YouTube is more ad-hoc and one-to-many in nature, these cohorts report that there is a sense of anonymity in their self-presentation, which allows them to treat the videos as an opportunity to be authentic and express themselves freely. A key informant explains:

“I like the fact that you can reach a very large audience. I also like the anonymity - you are broadcasting to people you don’t know. YouTube is unique in that honesty is appreciated. On YouTube, I feel as though I can be me” (YouTuber03).

iv. Building transactive relationships: Most key informants (8 out of 9) also shared that there were numerous offline and online relationships formed through the SMT. Some relationships were between YouTubers and their commenters and in some cases, these relationships were collaborative in nature, with other users volunteering to host, produce and edit videos for these informants. As one informant shared:
“My producers set up audio, video, lighting, and I set up the table, my background logo, etc., and get prepared for the recording. We work like clockwork together, and from start to finish its about an hour and a half, unless we get to chatting or planning on something else” (YouTuber09).

Further, some of these relationships, particularly between YouTube vloggers are transactive in nature where subscriptions are traded by YouTubers to increase the visibility and impact of their channels. One informant reveals:

“I follow over 200 channels, but I probably only actively engage with about half of that. Most of those are channels also subscribe to me, so those are the people I’ve connected with. I watch some more than others; I tend to be better about watching the YouTubers who watch me regularly as well. There's a mutual support there. I’ve unsubscribed to some, those who clearly weren’t watching me anymore, but that’s been pretty rare” (YouTuber06).

v. Coping with loneliness from chronic illness: It was also observed that for most of the study informants (8 out of 9), emotional exchanges on YouTube served to offer an escape from loneliness as one informant confirmed, saying:

“Between grad school and the fibro, I'm pretty isolated sometimes. On days when I'm stuck working at home or stuck in bed with pain and/or fatigue, I can still connect with people on YouTube. I can escape into their videos, see familiar and comforting faces, read their comments, etc. It makes me feel less alone some days” (YouTuber05).

3. Monetary/Financial benefits: Building a brand and monetization

It was clear that the potential of gaining monetary benefits from appropriation was a key incentive for these informants, particularly because some of them (7 out of 9) had limited employment options due to fibromyalgia’s effects on their ability to maintain a job or because they were retirees. Consequently, they sought to build brands and products that were directly linked to their YouTubing practices and make use of YouTube’s monetization policies. One informant (YouTuber01) had already attempted to create a brand and product around the concept of chronic illness identity, through T-shirts and mugs on Facebook. However, these had limited success and then she moved to YouTube to increase her viewership and reach a wider audience. Another
Informant (YouTuber07) used her channel to market the e-Book she wrote and was selling on Amazon about the effects of fibromyalgia on pregnancy.

It was observed that a major challenge experienced by these cohorts is that fibromyalgia as a vlogger brand is by default, a niche market. Therefore, they have smaller channels and reported that it was more challenging to meet the monetization policy setup by YouTube which requires that a channel have 1000 subscribers and 4000 hour of watch time (annually) in total to qualify for their partnership program. During the interviews and observations, it became apparent that several strategies were being applied to counter this restriction and increase “traffic and interest” for their channels, such as diversifying the topics that were covered in their videos.

There were two subthemes for this concept which are i) monetization and; ii) building a brand; these are presented in the next sections below:

i. **Monetization:** While YouTube provides monetization mechanisms through the partnership programs and advertising options, these paths were not available to all key informants as they had between 25 and 3000 subscribers. The default mechanism for monetization on the YouTube platform is through the partnership program, but these cohorts navigate this tricky restriction by explicitly requesting donations from subscribers on external third-party sites such as patreon.com⁸ or gofundme.com⁹. Although they could set up the monetization tools provided by YouTube, they were not able to benefit from it because of the smaller size of their channels, as an informant explains:

“I use AdSense and analytics. I also put out ads, but I just keep running out of money. It's really hard to grow a YouTube channel, that's based on health and on my life and stuff with barely any funds because I can't work and I'm trying to make money through Patreon” (YouTuber04).

Some key informants explained that these donation sites helped to compensate for the smaller size of their channels, which disqualify them from receiving any revenue from YouTube, as their viewer count, subscribers count, and other related

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⁸ https://www.patreon.com/

⁹ https://www.gofundme.com/
metrics fall below the established threshold for the YouTube partnership program and other monetization schemes.

**ii. Building a brand:** Some of the key informants indicate that vlogging about fibromyalgia is one component of their brand promotion strategies. Three informants were also cross-promoting their videos on other social media sites, selling customized content such as T-shirts, mugs, and books. This cross promotion was used to notify followers about new video uploads. One informant explains this, stating:

“This is one area where my background in media studies, social media, technical writing, etc. has been helpful. I may not have understood the technological side of YouTube when I started but I did understand the promotion and marketing side of things” (YouTuber06).

Additionally, these cohorts maintained the same/similar usernames on all platforms to ensure consistency.

**5.3.3 Effects of the YouTube environment on appropriation**

Key informants suggested that there is a thriving community around the content shared by a few YouTubers, who post fibromyalgia related content. Moreover, it was observed that the communities on YouTube consist of: 1) active vloggers; 2) subscribers and; 3) viewers who may or may not have accounts with YouTube. It should be noted that to interact with the channel beyond viewing and sharing, a logged in account is required (favouriting, liking, commenting).

Each YouTube user has a channel which has a description which provides the background information of the YouTuber for subscribers. In this context, it was clear that these descriptions were used by key informants to inform their subscribers of their connection to fibromyalgia, i.e. that they have received a formal diagnosis. Key informants suggested that another influence was due to the stringent policies that serve to control the activities and content of these vloggers on the YouTube website. Yet it was evident that the YouTube environment did not have formal mechanisms for controlling access to these ad-hoc communities, because any user with an account may comment or interact with any video uploaded to the site, unless comments are disabled for that video. Even in that case, any individual with a YouTube account (who is logged in) may view, like or dislike the uploaded comment. The YouTube environment
theme is further sub-divided into: 1) Quality of YouTube technology features and policies and; 2) Remaining a part of the community.

1. YouTube technology features and policies

It was evident that YouTube’s video-based communication mechanism was important to these informants because they found it more accommodating for their needs. One informant explains:

“I actually picked YouTube because I’m not very good with words and don’t feel I would be able to convey myself as clearly and articulately through just a blog (also, most of my pain is in my hands and arms, so sometimes typing can get to be too much, and thus, video is more accommodating to my pain)” (YouTuber02).

Aside from the video component, it was also clear that other features such as video tagging and analytics features were important and used by all key informants to promote content:

“I use tags to help my videos pop up when people are searching, and I can also see what topics are trending” (YouTuber05).

However, the majority (8 of 9) of the key informants were quite conscious of the limitations of YouTube technology, with some indicating that various features such as the notification systems, subscription system and chats were well known to be faulty. It was observed that, over the course of the study, YouTube announced that it would archive the former private messaging feature, as it was not being used by the community as demonstrated in Figure 5.3, below.
Figure 5.3 YouTube announces the retirement of the private messaging feature

This was replaced by an address-book based system where messages can only be shared with other users who are connections through email (the Gmail system). This update currently limits the messaging features to those users with Google plus accounts. Within the context of YouTube technology features and policies theme, three subthemes were identified as: i) staying within the guidelines of YouTube policies; ease of use and learning and; iii) openness of YouTube. These themes are presented below:

i. **Staying within the guidelines of YouTube policies:** It was evident that these informants made sure to comply with inbuilt terms of use policies of YouTube which constrain how users on the tool can create content. As one informant shares:

“The policies don't really affect me beyond knowing my content is fine to create. I hope to grow the channel and potentially monetise it but it's all slow going” (YouTuber07).

It was observed that YouTube had features like contentID to ensure that audio and visual content belonging to other artists is not used without permission. Further, when these media are used without permission, the YouTube algorithms generate a notification for the content owners who may file a claim to block, monetize or track the uploaded video content. Thus, to comply with the policies of YouTube, study informants shared that they often make use of the creative studio that has been provided for use by YouTube, as explained by an informant:
“As far as the creative studio goes, I use the music, and I've read the policies on monetizing and stuff, but I don't really use the help section to search for solutions. I only look up things on YouTube if it's a policy/rules question because I want to make sure I'm within the guidelines” (YouTuber06).

Otherwise these YouTubers have the option to produce their own audio and effects to avoid copyright strikes which could lead to channel deletion and the user to be banned from the platform.

ii. **Ease of use and learning:** It was suggested that the process of creating quality content and getting started as a YouTuber was challenging for these informants, as it required a level of technical competence and a steep learning curve. According to most (8 of 9) key informants, uploading a video at first seems uncomplicated, but there were several other issues they encountered, as they got more experienced. Creating quality videos required some expertise in video editing; required a high-quality camera; and an attractive video background. The key informants also shared that issues such as tagging and optimizing channels were not immediately obvious to them. Consequently, they turned to the community of other YouTubers to learn the basics:

“I found the experience very overwhelming at first. I had no idea what I was doing. I just jumped in feet first and started to utilize other channels to help me learn the best software to use, how to set up my channel, what other successful YouTubers were doing” (YouTuber06).

Further, more experienced vloggers often publish ‘getting started’-videos to guide other aspiring YouTubers:

“There are a lot of YouTubers who have made videos on how to start a channel and things they wish they'd known and advice they have” (YouTuber06).

When asked to explain, key informants further revealed the challenges of becoming a YouTuber: first, they needed to create and brand/design their channels. next, they had to learn the processes behind creating high-quality content. One informant explains this:

“The technical side of things was a shock! I didn't realize how difficult it would be. I think it took me 3 hours just to get a decent banner image. And I knew absolutely nothing about editing” (YouTuber06).
Because of the larger YouTube vlogger community who upload help videos and teach aspiring vloggers, these cohorts are better able to understand how to set up their channels. However, one informant found had a slightly different experience:

“I briefly researched how you did it and how to create videos and just started! It's very easy and accessible despite my limitations!” (YouTuber07).

iii. Openness of YouTube: Public YouTube videos are accessible to anyone with Internet access. Key informants all stated that this was a major motivation for their usage of the site. Because YouTube videos also appear in general internet searches through search engines such as Google and Bing, there is an opportunity for these videos to reach a larger audience than on any other social media site. As one informant explains:

“Not everyone is on Facebook, but everyone can watch YouTube” (YouTuber02).

2. Remaining a part of the community

It was clear that YouTube seems to support community formation around topics of interest. These communities could be formed ad-hoc around uploaded videos and comprised the YouTuber and commenters (who may also be YouTubers). Informants also shared that each cause or topic has its related community such as: chronic illness community, beauty vlogger community, tech vlogger community and so on which may be conducted on other social media sites:

“I am a part of #womenonYouTube or #femtube - which is just a group on Facebook of female YouTubers” (YouTuber06).

In keeping with the community aspect, it appears that there are some unspoken expectations within the community such as: to remain a central part of the community, the YouTuber is expected to continue to participate through the frequent upload of content. One of the key informants explains further:

“At it's heart YouTube is a social networking site like Twitter or Instagram or Facebook, but we communicate through videos rather than tweets or photos. So if you want to stay a central part of that community you have to continue to participate through uploading your videos and commenting on other creator's videos” (YouTuber03).
i. **Community expectations and scheduling content:** It was observed that, there are also some community norms which may take the form of challenges these YouTubers were expected to participate in by the community, such as #Storytime (a vlogger shares their personal story on a topic that is decided by their viewers) #Vlogtober (a video every day for the month of October) or #Vlogmas (a video every day of December until Christmas). One informant explains her posting schedule and its importance:

“My schedule was a bit off in December and January because I was trying to crank out all the travel vlogs (January) since I participated in Vlogmas. But I’m now back to my usual 3 uploads a week. It's very important to be consistent with uploads. It gives your viewers a sense of routine. They know they can count on you to produce new content” (YouTuber06).

ii. **Community norms and protection from trolling:** Although these channels allowed anyone with access to comment on videos, it appeared that the behaviour of community members have been moderated based on implicit norms that do not allow for negative citizenship behaviour such as trolling:

“I think smaller channels are more protected from that. Trolls get confidence from thinking the creator isn't going to read their comments. They do it more to stir up animosity with the other people in the comment section. And that doesn't really work on small channels because they know we read our comments and respond to them and there's more of a community that protects each other” (YouTuber06).

**5.3.4 Summary of findings**

This section outlines the key themes that were found in the YouTube case study.

- Process of appropriating YouTube for illness management
  - Viewing to vlogging
  - Building workarounds for YouTube features
  - Borderless appropriation of YouTube as part of a toolkit
- Individual incentives for adoption and continued use of YouTube for chronic illness management
Information support exchanges: Making sense of fibromyalgia and raising awareness

- Collective sensemaking to learn to cope with fibromyalgia
- Applying shared coping mechanisms
- Illness advocacy

Emotional support exchanges: YouTube as a safe space

- Fighting stigma and giving legitimacy to the "trash can disease"
- Crafting an illness identity
- Self-presentation as therapy
- Building transactive relationships
- Coping with loneliness from chronic illness:

Monetary/Financial benefits: Building a brand and monetization

- Monetization
- Building a brand

Effects of the YouTube environment on appropriation

YouTube technology features and policies

- Staying within the guidelines of YouTube policies
- Ease of use and learning
- Openness of YouTube

Remaining a part of the community

- Community expectations and scheduling content
- Community norms and protection from trolling

The next section provides a discussion of key findings from the YouTube study and outlines the identified affordances from this case.

5.4 DISCUSSION

This section discusses the influence and process of appropriation for the YouTube case study. A deeper discussion is provided in Chapter 9.


**Process of appropriating YouTube for illness management by chronically ill cohorts**

Concerning the process of appropriation, the diagnosis seemed to act as a trigger to initiate a distinctive set of appropriation actions for these informants. All the study informants shared that they had made the decision to become video bloggers after they had gotten diagnosed with fibromyalgia to create awareness. Yet, because of the niche nature of chronic illness, these informants faced challenges with regards to meeting the monetization criteria set up by YouTube. Therefore, these cohorts applied workarounds by using third-party applications like Patreon.com, GoFundMe.com and others to circumvent the policies set by YouTube and allow their subscribers directly donate funds to them. This finding is in line with previous studies that suggest that users may conduct workarounds to conform an IT artefact to their needs (Barrett 2018; Choudrie and Zamani 2016), in addition this finding aligns with previous studies that state that appropriation is a goal-oriented process (Grange and Benbasat 2011; Lamb and Kling 2003; Leonardi 2011).

Despite the challenges involved in appropriating YouTube, the inherent value of YouTube for these informants caused them to augment this technology through workarounds, indicating that YouTube’s usefulness was a significant influence on their continued use of the SMT (Davis 1989; Mendoza et al. 2010). For example, Informants had to conduct multiple workarounds to engage in YouTubing: 1) Integrating external technologies to create useful video clips (cameras, film production setup); 2) editing tools (software packages) to enhance the presentation of this content and; 3) integration of other SMTs to allow them to message others in their community.

Findings also suggest that these informants engage in borderless appropriation of SMTs involved appropriation of a suite of technologies alongside each other to complement their illness management practices and to support their efforts to build a brand as a chronic illness personality. Hence, these key informants reported having multiple SMT accounts across a range of technologies including Tumblr.com, Pinterest.com, YouNow.com and numerous others in addition to the SMT account they had for the case study. Some informants also suggested that they had accounts on illness-specific sites such as mdjunction.com- but interacted with those less because they were not as active or complete as YouTube that allows them to appropriate for numerous tasks and not just illness management.
Additionally, YouTube allows videos from the site to be embedded in other SMTs which allowed cross-platform promotion of uploaded videos which was seen as essential by these informants because it could serve as a way to drive up subscriptions and view counts which would impact monetization outcomes. In line with this concept, these informants maintain the same profile name across social media sites to increase their visibility and maintain brand consistency. This finding adds to previous research on the complementary use of media for different aspects of the same goal (Jung and Lyytinen 2014). These appropriation processes could be due to some positive qualities of the site such as the openness, global access and ease of integration into other social media sites. Findings from this present study show that the effects of the technology features of YouTube allows anyone with internet access to view created content without requiring an account to consume created content. This characteristic of YouTube was useful for these informants because they were able to drive up the view counts of their videos through cross-platform promotion and gain more visibility despite being a niche community on YouTube. Taken together, these characteristics seemed to mitigate the restrictions of YouTube such as the monetization threshold rules, copyright policies and ineffective communication features which served to constrain the extent to which its users could create content without risking account deletion.

**Influences on YouTube appropriation for chronic illness management**

First, the influences which were found in the YouTube case study are in line with and further unpack prior theory on the processes and influences on appropriation (Mendoza et al. 2010; Merolli et al. 2015; Wang et al. 2017). Findings from this case study also extend previous research on the role and effects of social media in the context of chronic illness (Goh et al. 2016; Liu and Pratt 2015; Merolli et al. 2013a, 2015; Wang et al. 2017). These findings suggest that: information exchanges aid with the task-related aspect of chronic illness management because it allows these informants to obtain information needed to better manage and cope with fibromyalgia. It seemed that the key informants’ appropriate YouTube because the experience of chronic illness was said to vary between individuals, therefore they were motivated to seek access to others treatment plans, crucial behavioural changes and coping information from videos uploaded by peers to YouTube. This finding is in line with previous scholars who had suggested that participation on social media in general.
could have positive influences on illness management by chronically ill cohorts by leading to patient empowerment (Househ et al. 2014; Rozenblum and Bates 2013).

Findings also revealed that information obtained from YouTube was often incorporated to varying degrees within the overall context of their individual illness management practices. Furthermore, appropriation of YouTube gave these informants an outlet to raise awareness about invisible illness and fight the associated stigma of chronic illness, empowering them to advocate for themselves in their care and with others who may not understand their illness.

Also, findings suggest that emotional exchanges with others in the community were an important motivation for these cohorts because these emotional exchanges allowed these cohorts to feel validated, accepted, protects them from isolation and serves to shield them from the stigma of an invisible, chronic disease. Accordingly, in line with previous studies that have examined the therapeutic effects of social media for self-presentation in general and chronic illness in particular (Coulson et al. 2017; Merolli et al. 2015; Schultze 2014), it was found that presenting oneself through YouTube videos was cathartic for these vulnerable cohorts because they were able to honestly express their experiences in an accepting community of others who could relate to their daily challenges.

Furthermore, in the context of chronically ill YouTubers, it was observed that authenticity, honesty and vulnerability were of value due to the nature of chronic illness. While social support was observed through the friendships created through YouTube, appeared that among YouTubers, it was transactive in nature based on tacit agreements to follow and engage with each other’s content. Further, these friendships emerged, as a sub-component of emotional support because for these vulnerable, isolated users there is an emotional need for companionship and understanding that is being satisfied through membership in the community. This case study also found that key informants tended to pursue material benefits, making use of mechanisms like YouTube’s analytics/monetization features to gain monetary benefits to sustain themselves.

The next section provides a set of identified affordances which enable (afford) positive illness management outcomes for the YouTube case.
Identified affordances which enable or disrupt positive illness outcomes

Because of the interactions between the incentives of the key informants, the influences and constraining structures exerted on these cohorts by the environment formed on the YouTube site, the following five affordances were observed.

**Self-presentation:** The process of sharing experiences with similar others in an immediate video format allows these cohorts to enjoy a therapeutic release. This affordance supports the concept that SMTs may provide chronically ill adults with therapeutic benefits (Merolli et al. 2015). This is partially influenced by the sense of anonymous sharing because there is no initial knowledge of who will view these videos and so these cohorts are able to freely present themselves in a controlled context to similar, understanding others without fear of judgment or ridicule. This sense of therapeutic release is supported by the technology features and protected by the community that ensure that these self-disclosure episodes are not subject to trolling or similar negative behaviour. Additionally, through this affordance, these cohorts obtain emotional support, fight illness stigma and offer informational support to their peers within the community.

**Identity:** YouTube allows these informants and their subscribers to develop a shared sense of identity. This emerges through shared terms and identification signals, such as spoonie, fibro-warrior and identifying with celebrities who are said to have the same illness. Similar to some previous studies, in the YouTube case, the identity affordance allowed some key informants take on a central position in the chronic illness network and assume the identity of a knowledgeable, empowered patient (Bernardi 2016; Pousti et al. 2014).

**A creative outlet:** As most informants reported, the YouTube SMT serves as an outlet for creative expression through the different processes involved in creating a channel, creating and editing content.

**Sensemaking:** The sensemaking affordance for chronically ill users refers to the extent to which the user is able to utilize the tool in making sense of their symptoms. This affordance may be realized before or after the official medical diagnosis by healthcare professionals.

**Storytelling:** YouTube allowed these cohorts the opportunity to share their daily lived experiences with others in the same condition online.
The next chapter presents findings from the Instagram case study.
Chapter 6: The Instagram case study

Illustrative quote: “I recently found [a] supporting group on Facebook and actually read what they wrote, and I was very impressed with what they said that happened to them. I felt that they told my story, I wanted to talk and tell them I went through but I was ashamed because I was in my social Facebook and did not want them to know my name, So I use Instagram because it gave me the option to keep two accounts open at a time and I had the idea of having one for people who understood and I did not have to pretend and another for people who think I’m ok” (Instagram07).

INTRODUCTION

Similar to the previous two Chapters, this Chapter presents the findings from the Instagram case study carried out to investigate the guiding research question for this thesis: How do chronically ill adults engage with and appropriate social media tools to better understand and manage their illness? The chapter proceeds with the case context which describes the background and relevant history of Instagram social media site in Section 6.1. Next, Section 6.2 provides the data collection strategy and analysis strategies including an overview of the key informants for the case including their antecedent experiences of living with fibromyalgia. Subsequently, the identified findings from the Instagram case are highlighted and presented in Section 6.3. These findings are demarcated into three dimensions: 1) process of appropriating Instagram for illness management; 2) individual incentives for adoption and continued use of Instagram and; 3) effects of the Instagram environment on appropriation for chronic illness management. The chapter concludes with a discussion in Section 6.4 and outlines affordances which act to enable or disrupt the process of appropriation of Instagram for self-management of chronic illness.

6.1 CONTEXT OF THE CASE

6.1.1 The Instagram social media tool: A brief background

Instagram is a mobile, desktop and internet based photo-sharing platform created in 2010 by Kevin Systrom and Mike Krieger, initially as an iOS device only application, but spread over time to Android, Windows and the web (Etherington 2016; Raymundo 2016). Instagram functions predominantly as a photo-sharing application
which allows users to upload, edit and share their photos with anybody who are either following them or who can access the website if the profile setting is not private. The vision statement for Instagram reflects this core capability: “Instagram is about capturing and sharing the world’s moments”. Instagram also allows sharing of time-limited (24-hour) multimedia content called stories. The web version of Instagram offers limited functionality compared to its mobile application by design as it is a primarily mobile oriented application. Therefore, features such as messaging, video and image upload with filters are better supported on its mobile application. The following are the main features of Instagram: accounts; profiles; Image sharing; activity feed; short video sharing; stories; direct messaging; hashtags and; search.

Account creation on Instagram is open to anyone and may be created either using an existing Facebook account or through a more traditional account creation process using an existing email address, creating a password and creating a unique username. Accounts on Instagram are considered different from the common understanding of profiles. Profiles on Instagram may be private or public and users may have up to five profiles attached to an account. Currently, Instagram has 800 million users globally and 500 million active daily users. Additionally, users on Instagram can locate content and other individuals using the search functionality to search by name or hashtags for topics of interest.

6.1.2 Being chronically ill on Instagram: challenges of living with fibromyalgia

Key informants shared that they had been living with fibromyalgia symptoms for years and the process of obtaining a diagnosis was: “like a series of elimination” (Instagram10). Some informants also had experienced a number of other chronic illnesses and allergies for years and they had a difficult time with obtaining a diagnosis, running a gauntlet of numerous wrong diagnosis because of lack of specific tests for fibromyalgia:

“I was going to doctor after doctor, all of them giving me different medications for different illness they thought it could be, then I would come back still in pain and then they wouldn’t know what to do with me anymore. they sent me to different kind of doctors like rheumatologists, traumatologists, orthopaedics etc. All they do is go through a very long list of possibilities and once they discard everything else and they have no idea of what else to do they just call it fibromyalgia- I hate that name. for me
it just means when they no longer can pinpoint to anything then they just call it that” (Instagram06).

Further, informants also shared that they faced daily challenges with their illness; stating that the physical and mental symptoms such as depression and fatigue that are experienced daily by these vulnerable cohorts caused them to feel isolated. The next section outlines the data collection and analysis strategies applied to this case.

6.2 DATA COLLECTION AND ANALYSIS

Qualitative data collection commenced with a search for publicly accessible posts tagged #fibromyalgia or #fibro on Instagram using the criteria specified in Chapter 3 (Refer to Chapter 3, Section 3.4.1). A screenshot of an example search result is illustrated in Figure 6.1, below. This search (see Figure 6.1 below for example) exposed the fibromyalgia related accounts and assess if the user might be eligible for inclusion in the study and returned 824,760 posts tagged with #fibromyalgia; 21,432 posts tagged #fibro.

![Figure 6.1 Instagram search results for the term fibromyalgia](image)

Next, the researcher carefully examined the profile information of the account, selecting only profiles confirming that the profile owner has fibromyalgia. Subsequently, messages (using the mobile version of the application because messaging is not supported on the web-based version of the application) were sent directly to 30 profiles with results that had appeared in the search phase after the associated account had been evaluated for inclusion. If the potential informant
demonstrated an interest in the study, email addresses were exchanged and a copy of the plain language statement describing the project, its aim; the expected activities that would be required from participants and consent form (see Appendix B) was sent to the potential participants.

Table 6.1 below outlines the demographic information of the key informants who participated in the semi-structured interviews from Instagram. Out of the 30 adults who were solicited, 15 did not respond to the messages, 5 declined to participate due to ill health and 10 adults ultimately consented to participate in the study. Each interview was 60-90 minutes long and conducted through chatting via Skype or Gmail chat function. Their key demographic characteristics are summarized in Table 6.1 below.

<table>
<thead>
<tr>
<th>Informant</th>
<th>Age Range</th>
<th>Location</th>
<th>Gender</th>
<th>self-reported level of efficacy with illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instagram01</td>
<td>25-30</td>
<td>United States</td>
<td>Female</td>
<td>Newly diagnosed</td>
</tr>
<tr>
<td>Instagram02</td>
<td>35-40</td>
<td>United States</td>
<td>Female</td>
<td>Transitioning patient</td>
</tr>
<tr>
<td>Instagram03</td>
<td>20-25</td>
<td>United States</td>
<td>Female</td>
<td>Experienced</td>
</tr>
<tr>
<td>Instagram04</td>
<td>25-30</td>
<td>United States</td>
<td>Female</td>
<td>Newly diagnosed</td>
</tr>
<tr>
<td>Instagram05</td>
<td>40-45</td>
<td>United States</td>
<td>Female</td>
<td>Experienced</td>
</tr>
<tr>
<td>Instagram06</td>
<td>20-25</td>
<td>United States</td>
<td>Female</td>
<td>Experienced</td>
</tr>
<tr>
<td>Instagram07</td>
<td>18</td>
<td>Spain</td>
<td>Female</td>
<td>Experienced</td>
</tr>
<tr>
<td>Instagram08</td>
<td>20-25</td>
<td>United States</td>
<td>Female</td>
<td>Experienced</td>
</tr>
<tr>
<td>Instagram09</td>
<td>20-25</td>
<td>Australia</td>
<td>Female</td>
<td>Transitioning patient</td>
</tr>
<tr>
<td>Instagram10</td>
<td>25-30</td>
<td>Australia</td>
<td>Female</td>
<td>Experienced</td>
</tr>
</tbody>
</table>

The data analytic strand commenced in tandem with the qualitative data collection phase (Refer to Chapter 3, Section 3.7) and was influenced by changes in the API guidelines and policies in June 2016 which restrict direct access. Therefore, the researcher utilized a third-party data service Picodash which was affiliated to Instagram for that purpose to extract open posts tagged with #fibromyalgia for the quantitative portion of the case study. Picodash is a data company that provides social media insights and advanced search functionality for the Instagram platform to journalists, researchers and brands in compliance with Instagram’s API usage policies. Therefore, Picodash provided data tagged with #fibromyalgia posted from 1st January 2015 until 13th September 2017 in .csv format. The Picodash service provided 77,843 posts that were tagged with #fibromyalgia which was cleansed and reduced to a sample of 700, spanning 1st January 2015 until 13th September 2017. This reduction also
involved the processes of data-cleaning as outlined in Chapter 3, Section 3.7.4. Finally, the captions were retained for analysis, because the methods that were used for analysis constrains the selection criteria of suitable data for analysis, limiting the selection to text content found in the image captions (Refer to Chapter 3, Section 3.7.4). The following section presents the findings from the case study of Instagram SMT.

6.3 FINDINGS

The key findings from the Instagram case are categorized into three broad dimensions: 1) process of appropriating Instagram for illness management; 2) individual incentives for adoption and continued use of Instagram and; 3) effects of the Instagram environment on appropriation for chronic illness management.

6.3.1 Process of appropriating Instagram for illness management

This set of themes is concerned how these participants interacted with Instagram, Table 6.2 below shows the descriptive statistics for the Instagram text corpus, the count column is concerned with the total number of posts that were included in the evaluation. There were 700 Instagram posts in the selected text corpus which had three types of interactions: reading; liking and commenting. The corpus did not contain any data on reading/lurking but showed that within the text corpus there was a range from 0-46 comments per post. It also showed that each post in the text corpus contained from 1-829 likes.

<table>
<thead>
<tr>
<th></th>
<th>Count</th>
<th>Mean</th>
<th>Std</th>
<th>Min</th>
<th>25%</th>
<th>50%</th>
<th>75%</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments</td>
<td>700</td>
<td>3.2</td>
<td>4.6</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>46</td>
</tr>
<tr>
<td>Likes</td>
<td>700</td>
<td>51.6</td>
<td>63.4</td>
<td>1</td>
<td>23</td>
<td>37</td>
<td>57</td>
<td>829</td>
</tr>
</tbody>
</table>

It seems that Instagram is considered an important part of the daily activities of key informants and the corresponding qualitative findings clearly show that Instagram was used daily by these cohorts to stay connected with the chronic illness community there, as an informant shared:

“I am active on Instagram daily. I continue to go on because I feel like I am helping people with my posts and I am also helping myself with staying positive despite what I have” (Instagram01).
For some, it was part of their daily practice to check Instagram several times a day or at least once a day, depending on their health or availability daily:

“Every day right before sleeping I scroll for a few minutes and maybe another 2 or 3 times a day whenever I have a moment and are free recently I haven’t been that active well not that recently it’s been like a month I think that I’ve become not too active at all as in sometimes not checking it for days in either of them but in average that would be what I do” (Instagram04).

To explore appropriation processes further in this context, the qualitative themes below provide more insight into the intricacies of appropriation for these cohorts on Instagram. The following section outlines the three themes that were identified during analysis concerning appropriation process of Instagram which are: 1) creating a separate account to compartmentalize fibromyalgia from “normal life; 2) borderless technology use and; 3) adaptive usage patterns to convey support on Instagram. These themes are presented below:

1. Creating a separate account to compartmentalize fibromyalgia from “normal life”

First, study informants shared that while they had adopted Instagram to connect with friends and family:

“Well I found out about Instagram through Facebook... I figured it was another way to connect with friends and make new ones also” (Instagram05).

It was observed that the majority of the study informants had created sub-profiles specifically for chronic illness. Talking about this issue, an informant shared:

“I joined on my personal account as it was a way to keep up with friends, but I joined with the fibromyalgia account, so I could use it to meet other people who are going through the same thing as me” (Instagram04).

Two study informants were siblings and reported that they rarely discussed their shared illness with each other although they physically lived in the same home:

“Absolutely, even though my sister has it, I look to Instagram a lot for information about fibro because we try to not talk about it too much between us” (Instagram09).
Rather, they both had profiles on Instagram for their illness practices and operated separately, each having their own group of “spoonies” that they followed.

“I think it has good and bad sides for separating. But then that reinforces the idea that I need to compartmentalise myself and sort of 'hide' parts of myself from 'normal' people (sometimes I call them 'muggles'). It's hard because I do want to advocate for awareness, but I can't always fight. and my identity is more than fibromyalgia, even though I can be consumed by it at times” (Instagram10).

2. Borderless technology use

It was observed that these participants also made use of other social media tools for other aspects of illness management. All key informants shared that they applied different social media tools for different aspects of illness management:

“I use primarily Instagram & Tumblr for blogging purposes/high traffic discussion of chronic illness content; secondarily Facebook for less personal information/used to update family and close friends” (Instagram08).

When asked to elaborate on which other social media tools were used and how these fit together in illness management practice, another informant shared:

“As of right now just Facebook and Instagram but I'm thinking of getting a Twitter but as of right now just those two. I still post things on Facebook as to spread awareness, so my family and close friends can understand what’s going on as well” (Instagram01).

For these cohorts, each social media tool appeared to have a specific role in their illness management toolkit:

“My social media goes in levels of how deeply I share content with people. in least to greatest: Facebook, Instagram, Tumblr. My Tumblr is extremely personal to me and some days it’s my sanctuary. I have maybe 3 people from my real life that follow my content and the rest are spoonie/chronic illness/support group/ common aesthetic interest pals” (Instagram08).

3. Adaptive usage patterns to convey support on Instagram

It was observed that there were numerous activities carried out by these cohorts to convey support to others in the chronic illness community on Instagram which
included posting memes, text-based posts, commenting and sending private messages to other members of the community. The comment below illustrates this notion:

“I enjoy posting memes and making memes and I talk to them privately or comment on their posts. I do that to show support and to let them know I can relate too and I’m not alone” (Instagram01).

Another informant confirmed this concept, sharing:

“I only really tend to use the picture posting feature and commenting and liking. I think I use the liking feature the most as it is an easy way to show someone that you liked that post and that you’re supporting them” (Instagram04).

In addition, it was also observed that following others allowed key informants to stay informed about others and show support:

“I follow a lot of the people and support them. I talk to them privately or comment on their posts. I do that to show support” (Instagram01).

**6.3.2 Individual incentives for adoption and continued use of Instagram during chronic illness management**

This set of themes is concerned with the background circumstances that led to the adoption of Instagram for chronic illness management purposes. First, as illustrated in Figure 6.2, a word cloud was used to visualize the most frequently appearing words and phrases to explore the text corpus from Instagram. Among the most frequently appearing topics were: Spoonie, Fibro warrior, pain and several other terms related to the fibromyalgia chronic illness community.
To gain a deeper understanding of the key themes of the Instagram text corpus, topic modelling using latent Dirichlet allocation (LDA), was applied to analyse the dataset (see Table 6.3 below) and identify the main topic groups. The key topical themes that were identified concerned: sharing information about illness symptoms (44%); seeking emotional support (32%); forming an illness identity (14%); soliciting monetary support (8%) and; inviting others to connect on other SMTs (2%).

Table 6.3 LDA topic modelling results for the Instagram text corpus

<table>
<thead>
<tr>
<th>Identified themes</th>
<th>Sample Sentence from Instagram text corpus</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sharing information about illness symptoms:</strong></td>
<td>“Because I don’t only have fibromyalgia”</td>
</tr>
<tr>
<td>refers to topic clusters that are about giving or receiving information about illness</td>
<td>ehlersdanlos costochondritis birthday butyoudontlooksick chronicallyawesome especially battle backpain fibropain exercise</td>
</tr>
<tr>
<td><strong>Percentage</strong></td>
<td>44</td>
</tr>
<tr>
<td><strong>Seeking emotional support:</strong></td>
<td>“This is my all-time favourite quote that I always like to go back to and share with others. It takes a lot more energy to be hateful so be kind always don’t judge others focus on yourself”</td>
</tr>
</tbody>
</table>
| represents topic clusters concerned with the exchange of empathy, caring or encouragement | butterfly fightingforacure brain fitbit adayintheifit chronicpainsucks effyourbeautystandards fitspo baby enjoy | 32

To gain a deeper understanding of the key themes of the Instagram text corpus, topic modelling using latent Dirichlet allocation (LDA), was applied to analyse the dataset (see Table 6.3 below) and identify the main topic groups. The key topical themes that were identified concerned: sharing information about illness symptoms (44%); seeking emotional support (32%); forming an illness identity (14%); soliciting monetary support (8%) and; inviting others to connect on other SMTs (2%).
Forming an illness identity: refers to topic clusters that are concerned with crafting an identity using terms common in the fibromyalgia community such as: warrior, spoonie or fibromite

| “Ok spoonies, it’s invisible disabilities week let’s see what sick people look like - show me your selfie” | everyday -auto immune disease -follow me fight fibro warrior fatigue crystal doctor baking chronicallyfabulous | 14 |

Soliciting monetary support: Denotes topic clusters concerned with obtaining or giving monetary or similar resources

| “New shirt alert! this design is raising awareness in the colour lavender as the awareness colour is purple. Check it out at the link in my bio” | fundraiser fun chronic life care eye eating benefit adhd car called | 8 |

Inviting others to connect on other SMTs: refers to topic clusters that discuss connecting through or following on other social media sites

| “At long last my blog is live and my first blog post is out please click on the link in my profile and subscribe to ensure that you get notified when my next post is out; I would love for you to join in” | Condition cure costochondritis fitness journey anxiety follow dream able create depression | 2 |

Because topic modelling only provides a high-level understanding of the individual incentives to adopt and continually use Instagram by these cohorts, it was important to gain deeper insights from the qualitative aspect of the study. The following section unpacks the four corresponding overarching qualitative themes (each with its own sub-themes) are outlined below which include: 1) information support exchanges to better manage living with fibromyalgia; 2) emotional support exchanges and validation, and; 3) monetary/financial benefits. These themes are presented in further detail below:

1. Information support exchanges to better manage living with fibromyalgia

Key informants shared that Instagram served as a space to learn from and inform others about various medication regimens, share research articles and coping strategies:

“It can definitely inform and help treatment and coping practices. Like you can learn about specific benefits and risks of certain medications or therapies” (Instagram10).
Because the experience of fibromyalgia varies between individual sufferers, it seemed that Instagram serves as a place to be exposed to others’ experiences and therefore learn about what works for others:

“It's good to see what treatment options people are trying though and seeing that there isn't a one size fits all way to treat chronic illness” (Instagram09).

Majority of the study informants (9 of 10) indicate that through participation on Instagram, they could (and still) learn how to better manage their illness. An informant explains:

“Having my account helps me learn more about fibromyalgia and help myself transition into a strong experienced patient as I go” (Instagram02).

These interactions involve discussions about symptoms, holistic treatment options, day to day coping practices, medications and other issues involved in illness management practices for these cohorts. As a result, Instagram was valuable to them for information exchanges, an informant explained:

“I keep participating (on Instagram) as it helps me to learn more about my conditions, because I learn from people who have experienced it for longer” (Instagram04).

For key informants, this was an opportunity to share their strategies for dealing with fibromyalgia that they had learned through experience, as an informant explains:

“I mostly post about how I deal with fibromyalgia I also post about different medications I take to cope with the pain, eating healthy and exercising spiritual messages and encouragement” (Instagram05).

Yet others explained that information shared on Instagram was useful sometimes but required discernment to avoid misinformation or scams:

“There is so much misinformation some things were really not worth reading” (Instagram07).

Information support had two main sub-themes which included: i) becoming an informed and empowered patient and ii); activism to spread awareness about fibromyalgia.
i. **Becoming an informed and empowered patient:** It was observed that these cohorts advocated for themselves with their GPs using information they had obtained from Instagram. Key informants disclosed that they had made use of information shared by others on Instagram to better understand their illness. Further, key informants indicate that their illness is not well understood by their GPs and so they preferred to gain knowledge from their peers who are more knowledgeable about disease progression, limitations caused by fibromyalgia and how to manage symptoms than their GPs:

“I often know more than my doctor does (about fibromyalgia) so most of the time it’s me saying what I need, and they just write the script or referral. Fibro and complex regional pain syndrome (CRPS) are still so confusing to GP’s so it’s hard to find one that comes up with new treatments you could look into.” (Instagram09).

This information was then utilized in discussions with their GPs or Rheumatologists to design illness management plans:

“If someone tells me about a medication they're on, I definitely ask my doctors to see what they think” (Instagram03).

Some informants also shared how this influenced them to seek a different set of medical practitioners who were better informed about fibromyalgia:

“Since having the fibro profile I have been more aware with my care when it comes to doctors. I have switched doctors due to talking to someone (on Instagram) that was being overly medicated, and my doctor was doing the same.” (Instagram01).

ii. **Activism to spread awareness about fibromyalgia:** Instagram served as a space where cohorts could raise awareness about fibromyalgia, particularly since it is termed an “invisible illness” 10 and diagnosis was difficult to obtain. Key informants indicated that they were driven to create more awareness of the difficulties faced by people with fibromyalgia, in part because the illness is considered “invisible” and was

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10 An invisible illness is a widely used umbrella term for medical conditions that are not easily visible to others, including chronic physical conditions and mental conditions
poorly understood because it presented with a plethora of other chronic illness. One informant explains her motivations:

“I created an Instagram account because I wanted to raise positivity and awareness to chronic illness” (Instagram01).

This activism was conducted for different aspects, it was observed that some informants primarily posted memes to inform others about the challenges of fibromyalgia, while one informant shared that she was an activist for numerous causes she had intimate experience with:

“I then started promoting my causes: domestic violence, chronic fatigue, chronic illnesses, mostly chronic illnesses such as fibromyalgia that's what I was diagnosed with about 5 years ago, domestic violence also because I’ve gone through that too.” (Instagram05).

Some informants were more invested in showcasing the day-to-day experiences of chronic illness sufferers by sharing their daily experiences, while others preferred to use images like memes to raise awareness about the daily experience.

2. Emotional support exchanges and validation

It was observed that informants shared posts that both offered and sought emotional support. When asked to elaborate, the majority of the key informants (7 of 10) explained that they felt better supported by Instagram than by their friends and families because they were interacting with similar others. Further, most informants (7 of 10) shared that Instagram was their primary source of emotional support:

“Nobody in my family or my immediate friends group understands what I'm dealing with so sometimes that's the only validation or support I get” (Instagram03).

While for some key informants (3 of 10), these exchanges served to supplement the support they received from their friends and families:

“I do have a pretty good support system outside of social media especially my husband, but they can only understand what I am going through to a certain extent” (Instagram01).

Nonetheless, all informants indicated that they regularly sought to offer and exchange encouraging posts with others in the community as indicated below:
“In times of great chaos and calamity, we make appreciation posts or ‘I’m thinking of you’ posts and tag as many people as we can. Kind of like an ‘I see you, I’ll be back soon’ because in times of great hardship we turn to each other and always have each other in our thoughts” (Instagram08).

In addition, most informants (9 of 10) reported that appropriation of Instagram triggers mixed emotions for them for various reasons. For instance, some informants explained that they felt discomfort from other members of the community who relied on them for significant emotional or health advice which affected their enjoyment of the community. One informant explains:

“It triggers both positive and negative [feelings]. It’s positive because I can relate to others or celebrate with others. If I’m not having a good day sometimes there’s great posts to read that are relatable. But it can be negative because sometimes there are posts that are very despairing and some people can be really down, and that can make me feel like that sometimes.” (Instagram10).

Consequently, a few informants reported that they had learned to try to avoid these encounters and protect themselves from these types of incidents:

“I try to be very selective about the people I follow and those that follow me... if one of my followers’ posts negativity or obscene things such as nude pictures or videos then I block them!” (Instagram05).

Supportive emotional exchanges and validation had three main sub-themes: i) therapeutic exchanges to combat isolation; ii) building borderless friendships and; iii) creating shared terminologies to craft shared identity.

i. **Therapeutic exchanges to combat isolation:** All key informants shared that the experience of fibromyalgia is isolating due to the physical and mental toll it takes on sufferers. It was observed that the interactions on Instagram helped to motivate the key informants and they also shared uplifting content to encourage others. For example, an informant said:

“I wanted to let people know they were not alone and that somebody else was going thru the same pain, feelings, and emotions they were. Sometimes it’s just nice to know you’re not alone. I use how bad others feel as an inner fight for myself to push forward for them and to show then you can live and push with a purpose” (Instagram02).
One informant explained how these exchanges were therapeutic for her:

“It is a relief for me to share things that I'm going through, I know it's cheesy, but its kind of therapeutic as I know that it's not people I know who are going to see it, so I can share it judgement and question free.” (Instagram04).

**ii. Building borderless friendships:** A recurrent theme in the interviews was a sense amongst interviewees that Instagram provided them with an opportunity to build friendships which transcended the technology. It was observed that friendships were forged on Instagram by most key informants and some of these friendships were quite close in nature, as one informant explains:

“I think I follow around 1,700 [others with fibro]. I love photos but I also just love reading peoples’ stories. I have about ten to fifteen accounts that I follow really closely but I try to scroll and comment and send people love as much as I can” (Instagram09).

In their accounts, the majority (7 of 10) indicated that they had developed close friendships with others in the same community. In all cases, the informants reported that they mostly interacted through Instagram or other social media, however, a few (3 of 10) informants had also met others from Instagram in real life:

“I've met one friend in person because she lives close by, and I've had pen pals I met through Instagram but I kind of stopped writing letters because I wasn’t able to sit up or write that much. I've talked to some people on WhatsApp” (Instagram03).

One informant reported that she did not have close friendships formed on Instagram:

“I do not speak with any other members in real life as I have not been on Instagram long enough to form any solid relationships with other people” (Instagram04).

**iii. Creating shared terminologies to craft shared identity:** It was observed that through interaction with others on Instagram, key informants created a shared identity and terminology which allowed them to better understand their energy limitations with fibromyalgia:

“I had never heard of the spoon theory until someone shared it on their page so now I use it every day: the spoon method gives you 12 spoons a day and
each activity you do uses one to three spoons. Once you use your spoons up then it’s time to rest your body. With fibromyalgia your energy goes very fast and you have to know when to stop” (Instagram05).

Key informants also shared that they also use these terms to locate one another on Instagram and identity other, as a key informant explains:

“I came across the term "spoonie" and immediately remembered The Spoon Theory and was like "these are my people!" so I began using Instagram” (Instagram02).

3. Monetary/Financial benefits: reaching a wider, targeted audience

A small number (2 of 10) of those interviewed shared that they were motivated to adopt and continue to use Instagram to build a brand around the concept of chronic illness. For example, an informant started an online based business including Instagram around the concept of beauty products for chronically ill individuals (see Figure 6.3, below), she shared:

“Instagram helps me keep up with my customers and community, and also by following someone, they know your blog/Instagram/company exists.” (Instagram04).

Figure 6.3 Profile page of Instagram04

For one other informant, she also carried out her general online business activities with the same fibromyalgia account, although the
“I only have one Instagram account that I use for everything - personal and business my reason for using Instagram is because I can reach more people faster to me than Facebook” (Instagram05).

6.3.3 Effects of the Instagram environment on appropriation for illness management

This set of themes are concerned with the environment provided for this cohort through Instagram. Each participant has an account and could have 1-5 profiles attached to this account. These profiles typically contain some information about the user, allowing others in the community to find fellow chronic illness sufferers:

“As a person who has experienced the chronic illness culture, I will say that I see name and illness mentioned the most in bios and introductory sections, it’s like our calling card at the library; like things are grouped together for convenience” (Instagram08).

Additionally, Instagram allows the formation of communities around hashtags and provides several features that allow users to share their lives with others who follow either the user profile, or the hashtag. When these profiles are set as public (default setting), any user on Instagram may access the post to like, comment or send a private message (direct messaging feature) to the poster.

Although the profiles of the study key informants were public, there is also an option to set privacy controls which restricts interaction with a profile to only an approved set of followers. The structure of Instagram enables these cohorts to create ad-hoc communities around posts, share videos, stories (pictures or videos which are only available for a 24-hour period) and text-based content. Therefore, these participants are able to continuously create and share content with other members of the community. The environment theme is further sub-divided into two themes: 1) accessibility and ease of use of Instagram; 2) technology features providing anonymity and privacy; 3) resistance to some features of Instagram and; 4) community formation through hash-tagging.

1. Accessibility and ease of use of Instagram

In all cases, the informants reported that Instagram was accessible and easy to use. For example, one informant shared:
“It's just that Instagram is more accessible for me. On Instagram you can ask a question as well and get lots of comments. It's just Instagram is more focused on pictures, memes and things like that” (Instagram01).

This was echoed by another informant who stated:

“I feel like Instagram makes it very easy to communicate with other members of the group as there is always the option to comment and it is an easy interface, sort of like a conversation” (Instagram04).

Concerning ease of use, an informant gave an example indicating the learning curve involved with utilizing Instagram from illness management:

“The live streams can be a bit awkward at first but when people start joining and start writing comments its great” (Instagram09).

2. Technology features providing anonymity and privacy

A common view reported by the study informants was that the decision to appropriate Instagram for use in the study informants’ chronic illness management practices was driven by features which allowed anonymity and privacy:

“Another reason I like to use Instagram is that I can maintain a lot of anonymity as I can choose the username and the name that shows, and they don't give any information like email address away or anything like that” (Instagram04).

The majority (9 of 10) of informants indicated that Instagram allows them to keep their personal profiles private, it was observed that majority of participants had separate accounts using either fibro or fibromyalgia in the name which may not include their own personal identifying details. For example, an informant shared her thoughts on this, explaining:

“Well my personal account I rather keep it private, I have only people I know basically and then in the other one is open to everyone and it’s not personal it’s not an account about me but like I say for fibro people who also trust God to in any way I can encourage” (Instagram06).

Similarly, another informant said:
“I don't always want my family and random people I went to high school knowing some details about my chronic illnesses and mental health” (Instagram09).

One informant disagreed, arguing:

“I only have one Instagram account that I use for everything: personal and business” (Instagram05).

One subtheme that was identified concerning technology features was the resistance to some technology features of Instagram.

i. Resistance to some features of Instagram: Although most (9 of 10) informants shared that they typically used all the features provided by Instagram, 1 informant seemed to be resistant to the newer features introduced by Instagram, sharing:

“I just post and I don’t use the going live or anything else. I wish they had never started the going live videos lol. It’s one thing to go live if you have something to say that will impact someone life for the better but to go live just because? Makes no sense to me but hey I’m almost 50 so different strokes for different folks!” (Instagram05).

3. Community formation through hash-tagging

A recurrent theme from the interviews was the sense of community among the participants on Instagram. Study informants revealed that through participation on Instagram they were able to be part of the chronic illness community, an informant explains:

“Our community creates an air of comfort, understanding, togetherness, and we constantly pull strength from one another” (Instagram08).

When asked to share how communities are formed on Instagram, another informant explained:

“Another thing about Instagram that is nice, is the hashtags. I know you can use them on Twitter and other social media, but there are limits on those, whereas on Instagram you can use as many as you feel you need to. This is also a great way to connect with other people by searching a certain hashtag and that way you know they post about similar things to you” (Instagram04).
6.3.4 Summary of findings

This section provides an outline to summarize key findings from the Instagram study.

- Process of appropriating Instagram for illness management
  - Creating a separate account to compartmentalize fibromyalgia from “normal life”
  - Borderless technology use
  - Adaptive usage patterns to convey support on Instagram

- Individual incentives for adoption and continued use of Instagram during chronic illness management
  - Information support exchanges to better manage living with fibromyalgia
    - Becoming an informed and empowered patient
    - Activism to spread awareness about fibromyalgia
  - Emotional support exchanges and validation
  - Therapeutic exchanges to combat isolation
    - Building borderless friendships
    - Creating shared terminologies to craft a shared identity
  - Monetary/Financial benefits: reaching a wider, targeted audience

- Effects from the Instagram environment on appropriation for illness management
  - Accessibility and ease of use of Instagram
  - Technology features providing anonymity and privacy
    - Resistance to some features of Instagram
  - Community formation through hash-tagging

The next section provides a discussion of key findings from the Instagram study and outlines the identified affordances from this case.
6.4 DISCUSSION

This section briefly discusses findings from the Instagram case study regarding the influences and processes of appropriation of Instagram SMT by these key informants. A deeper discussion is provided in Chapter 9.

Process of appropriating Instagram for illness management by chronically ill cohorts

Findings support three main concepts concerning Instagram appropriation. Adoption of Instagram was voluntary, to share and view content from friends and family. Yet, it was clear that for most informant’s illness management related activities served to trigger a distinctly unique process. Because of the stigma of fibromyalgia, the majority of key informants created separate profiles to conduct illness management activities and compartmentalize fibromyalgia from their other Instagram activities.

In addition to Instagram, all key informants also had SMT accounts on other sites which were applying to carry out different aspects of their illness management needs. For instance, Tumblr was used to share poetry and other more personal thought, like a virtual diary, while Facebook was used for less personal reasons. In addition, other activities like posting, commenting and following were for conveying support on Instagram.

Influences on Instagram appropriation for chronic illness management

For informants in this study, it seems that the experience of living with fibromyalgia permeates all facets of the lives of its sufferers as they deal with chronic pain, fatigue and other related illnesses. Findings indicate that information support exchanges served as a strong incentive to adopt and use Instagram SMT because, through interaction with others, they could stay informed on others treatment and coping plans which aided their self-management practices. This finding supports prior literature that suggested that SMTs could serve as a valuable source of illness management information (Wang et al. 2017). Moreover, through information support exchanges they could engage in activism about fibromyalgia which these key informants felt was misunderstood and overlooked by their healthcare providers. Further, these exchanges served to help key informants empower themselves and advocate for better care with their GPs or rheumatologists. This finding supports prior research which had proposed the notion of SMTs helping to create empowered patients
who would be active participants in managing their care (Bodenheimer 2002; Househ et al. 2014).

Emotional support exchanges were also found to be a significant incentive to continually use Instagram SMT because most key informants shared that they were unable to get understanding from their family or healthcare providers about the day to day challenges they faced with this debilitating illness. In line with previous studies, findings indicate that these exchanges were a therapeutic outlet because key informants could share and receive positive uplifting content to cope with the mental toll of fibromyalgia (Merolli et al. 2015). Further, through the adoption of Instagram, relationships were formed and served as a buffer from the loneliness experienced due to the challenges of an invisible chronic illness (Cohen and McKay 1984; Cohen and Wills 1985; Lazarus 1993). This allowed the development of shared identity or terms, these terms included phrases like “fibro-warrior” and helped informants find others with the same illness on the SMT. It was also observed that the opportunity to gain monetary benefits was an incentive for some informants to circumvent the financial challenges of being chronically ill and therefore, unable to work. This ties in with the concept of identity, because these monetary benefits were crafted around the brand of chronic illness allowing them to gain material support as proposed in previous studies (Barrera 1986; Lakey and Cohen 2000; Shumaker et al. 1984).

Further, Instagram was a source of structure which exerted influence on appropriation in terms of providing an environment where communities could be formed around content such as posts or hashtags (Orlikowski 1992; Schmitz et al. 2016). The features of Instagram SMT allowed the creation of ad-hoc communities where users could traverse and find others through viewing shared content or profile information. Because Instagram SMT was a low cost, accessible environment which was easy to use it, therefore, supported these informants in their illness management practices. This set of findings support prior work which stated that ease of use or cost could serve to influence appropriation outcomes (Davis 1989; Venkatesh et al. 2012). Moreover, through the technology features of Instagram, key informants were able to maintain private profiles separate from their default Instagram account and so compartmentalize their illness management practices. As a result of this feature, Instagram helped key informants escape the stigma or embarrassment of exposing friends and family members to the daily struggles of life with fibromyalgia. This
allowed the creation of a safe space and they were able to present their content to a community of similar others (Mendoza et al. 2010; Riemer and Johnston 2012).

The next section provides outlines various affordances identified by the researcher during the case study.

**Identified affordances which enable or disrupt positive illness outcomes**

Because of the interactions between the motivations of the study cohorts and the influences and constraining structures exerted on these cohorts by the environment formed on the Instagram site, the following affordances were observed.

- **Therapeutic self-expression:** The process of sharing experiences with similar others in and through specialized profiles allows these cohorts to enjoy self-presentation. This is partially influenced by the sense of private sharing because cohorts are able to freely express their illness management needs to similar, understanding others without fear of judgment or ridicule. Additionally, through this affordance, these cohorts obtain emotional support, fight illness stigma and offer informational support to their peers within the community.

- **Ad-hoc community affiliation:** Instagram affords these cohorts the ability to affiliate with a community of others who are connected by a shared condition, as a consequence of the hashtagging community formation feature provided by the SMT.

- **Compartmentalization:** This affordance allowed key informants to operate in their illness management profiles, separate from the profiles followed by other members of their offline network.

- **A creative outlet:** Instagram SMT serves as an outlet for creative expression through the different processes involved in creating a channel, creating and editing content.

- **Identity:** Identity was seen to allows chronically ill users to craft identities around their illness such as spoonie and through the use of the fibromyalgia butterfly.

The next chapter, therefore, moves on to discuss the findings from the Facebook case study.
Chapter 7: The Facebook case study

INTRODUCTION

The previous chapter (Chapter 6) presented the findings from the case study with mixed methods of chronically ill adults on Instagram SMT. Similarly, this chapter presents the findings from the Facebook case study to address the guiding research question for this thesis: How do chronically ill adults engage with and appropriate social media tools to better understand and manage their illness? The chapter proceeds with Section 7.1 which describes the case context which describes the background and relevant history of the Facebook social media site. Next Section 7.2 outlines the data collection strategy for this case including an overview of the key informants and their antecedent experiences to appropriation of Facebook. Subsequently, Section 7.3 presents key findings from the case study. These findings are demarcated into three aggregate dimensions: 1) process of appropriating Facebook for chronic illness management; 2) individual incentives for adoption and use of Facebook and; 3) effects of the Facebook environment on appropriation for chronic illness management. The chapter concludes with a discussion in Section 7.4 and outlines affordances which act to enable or disrupt the process of appropriation of Facebook for chronic illness.

7.1 CONTEXT OF THE CASE

7.1.1 The Facebook social media tool: A brief background

Facebook is a free to use social networking platform founded by Mark Zuckerberg, Eduardo Saverin, Dustin Moskovitz and Chris Hughes on February 04 2004 (Carlson 2010; Philips 2007; Zeevi 2013). It comprises desktop, mobile and internet-based services to support social networking. Facebook as a platform consists of a social networking site which is comprised of a user’s profile, newsfeed, friends, real-time instant messaging, entertainment features, universal login, groups, pages,

11 Selected findings from this case were presented in a full research paper at Australasian conference of information systems (ACIS) 2018
events and other features that allow users to connect with friends, family and similar others globally.

Additionally, the platform contains support for business insights and targeted advertising for brands. Also, Facebook provides an API integration endpoint (graph API) for the development of applications and web services that integrate or use some of the functionality from the site. Figure 7.1 below indicates the profile page from a Facebook account, the home page consists of streams of news from followed pages. In addition, stories from friends and followed pages are presented to the user on the left-hand side. Next, the right-hand side of the page displays shortcuts to access networking functions such as messaging, groups and the market place for purchase/sale of items.

![Facebook Home Page](image)

Figure 7.1 The Facebook home page

### 7.1.2 Initial capabilities and vision

Facebook was initially created as a rating site, where Harvard University students could rate their peers based on their perceived attractiveness (Philips 2007; Zeevi 2013). However, over time, its vision and core capabilities have been revamped from a focus on user ratings to a social networking focus; with features that support profile creation, instant messaging, content generation, content sharing, entertainment, event creation and group formation. Therefore, the company recently unveiled a new
vision: “To give people the power to build community and bring the world closer together.”, this vision encapsulates a strategic shift from a focus on status updates to a more community-oriented vision for the company (Newton 2017; Reagan 2009). The groups and pages capability of Facebook are illustrative of some of the features that support this vision, and they are outlined below.

**Facebook groups:** Facebook groups may be created by individuals or organizations to attract peers with a common interest such as: causes, lifestyle, support and fan groups. Membership to a group involves sending a request for membership and then obtaining acceptance by the administrator, owner or moderator of the group. Groups have certain levels of visibility built-in based on the group type: public, closed and secret. Public groups have their posts, files, and membership information open for view to anyone who has access to the internet. Closed groups are visible in an online search; with the group description also visible to anyone with an internet connection; however, posts, members and files are hidden to anyone who is not a member of the group. Secret groups have the lowest level of visibility, with membership only occurring because of an invitation by either a member of the group or the administrator(s) /owner/moderator of the group.

**Facebook pages:** A Facebook page may be created by any user or organization around a common interest or cause. Pages on Facebook do not have members, however, but have fans that may follow, post and comment on the page. Unlike the group feature, a published page’s actions and fans are visible to anyone with an internet connection.

### 7.1.3 Being chronically ill on Facebook: Challenges of living with fibromyalgia

Facebook is the most adopted social media tool in the world and serves to connect individuals globally, as outlined above, Facebook supports groups and pages based on interest. Accordingly, there are several chronically ill users who join groups, follow pages and interact with others on the site around the topic of their chronic illness. Majority of the study informants indicated that they had joined the groups and followed fibromyalgia pages after being diagnosed with fibromyalgia or when they were searching for a diagnosis that fit the symptoms they were experiencing. Due to the physical toll of fibromyalgia, an offline support group was not always an option because fibromyalgia symptoms include chronic pain and chronic fatigue. In addition
to the physical limitations of the illness, there were also issues that acted as a barrier to obtaining support offline such as: Financial restrictions and lack of specialized support groups in their areas. Consequently, they took advantage of the groups and pages feature on Facebook to obtain support while managing their illness.

The next section discusses the data collection and analysis procedures that were applied to the Facebook case study.

7.2 DATA COLLECTION AND ANALYSIS

The Facebook data collection process commenced with a search for: “fibromyalgia” or “fibro” on Facebook.com. The search returned 270 groups and 492 pages connected with fibromyalgia; the researcher then sent messages to 15 administrator/moderators of 10 groups to seek permission to join, in accordance with the data collection strategy outlined in Chapter 3 (Refer to Chapter 3, section 3.5.1). Out of the 15-group administrator/moderators contacted, 8 agreed to participate in the study, however, during this time of recruitment 2 administrators dropped out. Out of the remaining 6 groups, 4 completed the semi-structured interviews and informed members of their respective groups of the study, after which an additional 7 members across the groups consented to and completed the semi-structured interviews.

There were 12 key informants in total and 8 were based in the United States, with 4 being based in Australia, and all informants being characterized in one of three categories: newly diagnosed, transitioning or experienced (see Table 7.1).

Table 7.1 Background summary of key informants for the qualitative portion of the Facebook case

<table>
<thead>
<tr>
<th>Key informant</th>
<th>Sex</th>
<th>Age Group</th>
<th>Location</th>
<th>Reported level of self-efficacy with illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facebook01</td>
<td>Female</td>
<td>45-50</td>
<td>United States</td>
<td>Experienced</td>
</tr>
<tr>
<td>Facebook02</td>
<td>Female</td>
<td>45-50</td>
<td>Australia</td>
<td>Experienced</td>
</tr>
<tr>
<td>Facebook03</td>
<td>Female</td>
<td>25-30</td>
<td>United States</td>
<td>Newly Diagnosed</td>
</tr>
<tr>
<td>Facebook04</td>
<td>Male</td>
<td>40-45</td>
<td>Australia</td>
<td>Experienced</td>
</tr>
<tr>
<td>Facebook05</td>
<td>Female</td>
<td>35-40</td>
<td>Australia</td>
<td>Experienced</td>
</tr>
<tr>
<td>Facebook06</td>
<td>Female</td>
<td>65-70</td>
<td>United States</td>
<td>Experienced</td>
</tr>
<tr>
<td>Facebook07</td>
<td>Female</td>
<td>45-50</td>
<td>United States</td>
<td>Experienced</td>
</tr>
<tr>
<td>Facebook08</td>
<td>Male</td>
<td>35-40</td>
<td>United States</td>
<td>Experienced</td>
</tr>
<tr>
<td>Facebook09</td>
<td>Female</td>
<td>35-40</td>
<td>United States</td>
<td>Experienced</td>
</tr>
<tr>
<td>Facebook10</td>
<td>Female</td>
<td>30-35</td>
<td>United States</td>
<td>Transitioning patient</td>
</tr>
<tr>
<td>Facebook11</td>
<td>Female</td>
<td>30-35</td>
<td>United States</td>
<td>Newly Diagnosed</td>
</tr>
<tr>
<td>Facebook12</td>
<td>Female</td>
<td>25-30</td>
<td>Australia</td>
<td>Experienced</td>
</tr>
</tbody>
</table>

The researcher also observed 3 of the groups for 20 hours over a nine-month period to understand how Facebook was appropriated during illness management.
practices of adults with fibromyalgia. The observation conducted in the qualitative portion of the study included video, images, text and a holistic examination of interactions on the site because observations are better suited to interpreting that content. This allowed for an investigation of actual appropriation behaviour within the natural setting (Strauss and Corbin 2008; Yin 2013). In addition, one group administrator provided the researcher with access to usage and administration data for the group, to augment observations and yield deeper insights. For the quantitative analysis portion of the study, a Facebook page was selected, because Facebook pages are open to access, therefore the researcher could freely collect and analyse data in compliance with the terms of use of Facebook. A Facebook page from the community category was selected because pages from that category had more interaction with their fans, allowing them to post and contained less advertisement material than pages in the other categories.

Also, the selected page was suggested by the page owner (also an informant) and followed by some of the key informants of this case study during the semi-structured interviews. The researcher collected data posted from 1st January 2015 until 13th September 2017 using the Netvizz browser plugin. The collected data corpus contained 11,786 posts which were a mixture of links from other websites; photos and text posts, from this dataset data-cleaning was conducted in line with the strategy outlined in previous chapters (Refer to Chapter 3, Section 3.5.2). From the resulting cleaned dataset, 700 text posts were sampled for further data analysis in this study. The following section presents key findings from the case study of Facebook SMT.

7.3 FINDINGS

The findings from the Facebook case study are demarcated under three broad theme categories: 1) process of appropriating Facebook for illness management; 2) individual incentives for adoption and continued use of Facebook and; 3) effects of the Facebook environment on appropriation.

7.3.1 Process of appropriating Facebook for illness management

The text corpus contained interaction metrics for the selected Facebook page which had 90,635 followers from 45 countries. The majority of its followers were from the United States (59.12%), followed by Great Britain (26.42%) and Canada (4.7%). Further, the Facebook page sample contained 7,933 comments, 24,401 reactions and
1,048 shares and the total number of followers of the page was 90,635. Additional interaction metrics from the Facebook group showed that over the observation period the total number of posts was 782, with 4,233 comments, 29,287 views and 14,286 reactions. Key informants shared that the community comprised a group of active members who react, post and comment on each other’s content yet it appears that a larger proportion of members read the contents on the community, but don’t interact further than that as one key informant explained: “There is a core group of active members, who comment on each other’s posts and really make an effort to support each other in a positive way. There is also a larger group of silent members, who rarely comment, but like to read everything that is going on in the group.” (Facebook02).

It became apparent that Facebook became an important part of the daily lives of these key informants, with some spending most of their day on Facebook. All key informants shared that they were consistently notified about new posts, comments on the group but mostly interacted daily to be aware of events that occurred in the group as one informant explained: “Well I try to check daily and I only post if I have some knowledge or I have a question really.” (Facebook05). However, for those informants in an administrative role, this daily interaction was a necessary part of their role but was considered part of the expected workload as an administrator. One informant who is an admin explains: “I seem to be spending all day on FB at times but at present I am training some people which adds to the workload.” (Facebook05). Five appropriation patterns were observed: (1) lurking as passive learning; (2) liking and reacting to show support; (3) posting and commenting to exchange information and; (4) borderless technology appropriation.

1. Lurking as passive learning

Key informants shared that newcomers practiced lurking initially, reading through posts to familiarize themselves with community norms. It was observed that for the new members, after lurking they often announced themselves using this common statement: “first time poster, long time lurker”. When asked, about this, some key informants indicated that they often lurked passively consume content. One informant explains: “I read everything if I'm online and if I don't have anything to say I don't emoticon it or post to the thread.” (Facebook05). For some, they preferred to discuss privately. An admin explained further concerning the lurkers in the
community, indicating that they often preferred interaction through other less visible mechanisms e.g. private messaging: “Some prefer to personal message an admin with a question, others interact on the page” (Facebook04).

2. Liking and reacting to show support

Most key informants (7 out of 12) preferred interaction with the community through the liking and reacting feature of Facebook. Hence, liking or reacting was used to participate within the community while retaining some privacy, while also showed support to others in the group. One informant explained the value of a like: “Likes are also important, people like their posts to be liked because many are nervous about sharing” (Facebook09).

3. Posting and commenting to exchange information

It was observed that half of the key informants rarely made new posts but regularly followed up with comments or questions to the community as one informant noted: “I've made one post thus far, but I comment if I know something or have a suggestion or share experiences or I have a question.” (Facebook06). Key informants shared that posting served two main reasons: to encourage interactions on the group and to pose questions that were not already discussed in the community. Commenting seemed also a means of showing support and sharing personal experiences with peers: “Well I like commenting because I like sharing my thoughts about the topic in the post as it relates to me or my experiences. I also do liking to show support to others opinions too.” (Facebook09).

4. Borderless technology appropriation

Most (9) key informants shared that they also used several other social media technologies along with Facebook to augment their illness management needs, such as using the Facebook group to track symptoms and progression of their illness and some other technologies. One informant confirmed this: “I'm on Instagram, my space, oovoo, tango, and snap chat. [The] Facebook [fibromyalgia group] is the one I'm on the most.” (Facebook01). A few (3) others didn’t have the time to learn new technologies due to limited time to spend online due to life situations and other obligations as one informant explained: “I don't have the time or the energy for any other social media sites.” (Facebook02).
7.3.2 Individual incentives for adoption and continued use of Facebook for chronic illness management

First, the Facebook text corpus was explored to characterize its content using a word-cloud generated with Python. Figure 7.2 below illustrates the results in a word cloud. The most frequently used words in the dataset are related to obtaining help from others in the community. In addition, other frequently occurring words include doctor, symptoms, diagnosed and other related terms.

![Word cloud illustrating the most frequently appearing words in the Facebook dataset](image)

While the word cloud provided a broad overview of the most frequently appearing words within the text corpus, it was not sufficient for identifying the most salient themes from within the dataset because it lacked contextualization and so would not provide sufficient contextual information about surrounding topics to enable accurate interpretation to a higher-level theme. Therefore, the researcher conducted topic modelling using latent Dirichlet allocation (LDA) to extract more meaningful topic clusters.

This LDA extracted the 50 most salient topics from the text corpus which were represented through 10 terms per topic, from 5 core themes were interpreted based on the analysis method described (see Chapter 3, Section 3.5.4). From those, the identified themes were related to: Seeking Information Support (84%), Offering Emotional Support/Comfort (10%), Seeking access to a community (4%), and Identifying with other members of the group (2%).

Table 7.2 below demonstrates a subset of the 50 topics derived from LDA.
Table 7.2 Topic modelling results of latent Dirichlet allocation

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sample sentence from the Facebook dataset</th>
<th>Sample topic group from LDA</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeking Information Support</td>
<td>“Hi everyone, I'm new to the group and recently diagnosed with fibromyalgia. I'm 28 and I guess I'm wondering if my symptoms are 'normal' for fibromyalgia......Does anyone else get that? And what do you do to help it?...”</td>
<td>fibromyalgia hello thyroid medicine lately arthritis cause eye disease annoying</td>
<td>84</td>
</tr>
<tr>
<td>Offering Emotional Support/Comfort</td>
<td>“…gentle hugs to all my awesome fibro friends x”</td>
<td>pour page hug normal mri extra infection pas pulled feel</td>
<td>10</td>
</tr>
<tr>
<td>Seeking access to community</td>
<td>“Can u message me please I’m having problems with members group page”</td>
<td>late head close group person ankle reply letter school really</td>
<td>4</td>
</tr>
<tr>
<td>Identifying with other members of the group</td>
<td>“Hi fellow fibro warriors…..”</td>
<td>spoonie post hip planter warrior starting want Tuesday flare sky</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td>100</td>
</tr>
</tbody>
</table>

The qualitative themes below were extracted from interviews with key informants and their commenters and are presented in further detail below.

1. **Information support: Making sense of fibromyalgia and raising awareness**

A major theme that was identified related to information support to make sense of and cope with Fibromyalgia. It was observed that these cohorts use Facebook to learn more about how to better manage the day-to-day impact of fibromyalgia on their lives.

“And my reason for joining this group is to educate myself a bit I’m finding what a lot of other people are going through. I’ve got a lot more answers from this group just reading threads than I did off doctors” (Facebook05)

Further, it seemed that these exchanges ranged from some informants sharing information about holistic remedies while others were more concerned with obtaining information about medications, their effects and how to obtain a correct diagnosis for their ailments. It was apparent that more experienced cohort tried to assist newly diagnosed/yet undiagnosed participants with coping strategies and inform them what to expect as the illness progresses.
Key informants shared that issues discussed include topics such as medications, symptoms, gaining government support for disability or legislative issues: “I was approved the first time around for my disability, so I offer insight from a nursing perspective and documentation to help people” (Facebook07). The following sections discuss the subthemes that arise from the information support theme:

   **i. Increased understanding and illness advocacy:** It appeared that through use of these Facebook groups and pages these cohorts were able to an opportunity to educate their peers and members of the public on fibromyalgia. For most (8) key informants, this was essential particularly since fibromyalgia is through a process of elimination, termed by sufferers as an “invisible illness”, not well-supported by the medical community and so, all key informants shared that they face huge obstacles to obtaining support and through participating on these pages/groups they could make the invisible illness visible. One informant explains the challenge:

   “I often followed the new information that was being shared online but my new pain doctor wouldn’t try the new medications even though I brought him some research to read.” (Facebook06).

Key informants shared that they were motivated by access to information from others about their self-management strategies which could aid them in advocating for themselves to receive care and support. One informant explained:

   “I participate so that I can advocate for myself with doctors with the new info I may get from the group.” (Facebook09).

Another key informant agreed and shared that this also involved sharing information about how to obtain financial aid, since fibromyalgia is classified as a disability:

   “I was approved the first time around for my disability claim, so I offer insight from a nursing perspective and documentation to help people.” (Facebook07).

Another informant explains her perspective on the potential value of the Facebook group and motivation for continued use: “It didn't help me to get diagnosed but they helped me when Doctors wouldn't believe or have an opinion on obscure symptoms and I would go on every so often and ask a question about these random symptoms and find that they are not so medically recognized but they are definitely a part of the experience and I'm not alone.” (Facebook12).
ii. Communal filtering through misinformation/spam: Key informants shared that although these groups attempt to monitor shared content, they had to cope with misinformation and spam challenges as one informant explained: “Misinformation is also something (to be aware of) as there are so many cures out there. One member tried to sell miracle water via personal message she was blocked and posted about on the site, but this is an extreme measure.” (Facebook04).

Additionally, it was observed by the researcher and confirmed by some key informants that spammers often attempted to phish data about group members through the URLs posted linking these to sites with malware and viruses: “There is a company in Pakistan that does that. There are also those doing it (phishing attacks) giving away iPhones to gain information and the ones with pop up ads telling you your computer or phone is infected ring this number.” (Facebook04).

Yet, some informants (3) reported that although the group took serious measures to protect members from these negative actions, some unscrupulous scammers formed private chats to privately scam vulnerable members of the group: “I have people selling things whom I chat with on messenger, some of the fringe science used is really interesting.” (Facebook04).

iii. Applying shared coping mechanisms: It was also observed that apart from discussing major fibromyalgia symptoms, these informants also exchanged advice to help the management of secondary symptoms of fibromyalgia. Key informants confirmed the value of these exchanges and revealed that they regularly apply the tips and suggestions from peers into their daily illness management practices, one informant elaborates on this, stating: “You get info that could be useful to you too. I started to get my medical marijuana card for pain management largely because of the positive feedback I got from other members.” (Facebook09). Among the therapies that were reportedly applied by the key informants because of suggestions on were: acupuncture, medical marijuana, weighted blankets and other holistic strategies. These also related to what supplements to take and how to take them for optimal results, as an informant explains: “For example- someone posted that Magnesium supplements interfere with the absorption of the medication Synthroid--so I just checked this am and found it to be true. So, Magnesium has to be taken at least 4 hours AFTER taking thyroid medication.” (Facebook07).
2. Emotional support exchanges: coping with the burden of fibromyalgia

It appeared that another major motivation was to exchange emotional support with similar others. Key informants shared that Facebook appropriation had a mixed impact on their emotional well-being, ranging from positive emotional experiences from being in these communities; a sense of belonging, exchanged empathy and fulfillment helping others through shared experiences. One informant explains:

“As a closed group, members feel free to express their innermost frustrations about having a chronic illness, so the group focus is more on support and shared experiences. We have and receive an empathetic ear and can joke around and keep each other in a positive frame of mind.” (Facebook02)

However, all key informants shared that it could sometimes be depressing, and they had to find the right balance to protect their mental well-being: “Sometimes some of the posts are overwhelming depressing. I have to not allow myself to become too emotionally involved. So, I have to show empathy and sympathy and compassion without becoming too depressed.” (Facebook01)

It was observed that some member posts expressed suicidal feeling and were negative emotionally charged group posts which these groups were not equipped to handle as an admin explains: “Our job is only to Admin. We are not trained counsellors and do not have the energy to engage in individual support for members. However, if there is a direct threat of suicide we have on occasion reported to Facebook or the police/medical services in the members district if known.” (Facebook03).

Consequently, some members struggled with the barrage of negative posts and stories shared as an informant confirms: “All I see is negative posts and I think why I bother even being in a support group if everyone is so negative.” Additionally, trolling contributed to the negative emotional impact from appropriating these technologies as one informant shared: “The guy just went bonkers and yeah, I ended up deleting my post, my mum even saw it and all quite disheartening I cried for a few days after deleting the thread.” (Facebook03). These subthemes are discussed below:

i. Dealing with illness stigma as a community: Key informants shared that Fibromyalgia often manifests with no visible symptoms and there are no specific medical tests that may be used to conclusively offer a diagnosis. Hence, rheumatologists often carry out diagnoses but getting diagnosed and obtaining and
Chapter 7: The Facebook case study

effective treatment options seems to be challenging. An informant explains: “[we are] a disenfranchised group of chronically ill people whose medical condition is misunderstood and often ridiculed by many in the medical profession and the society as a whole.” (Facebook02). Key informants shared that this premise played out during daily activities when informants were limited by fibro flares from actively participating in family activities or chores which caused friction with their families. It was observed that when these members shared these experiences, other members of the group related to this experience and posted with supporting comments, reactions and gifs to show support to a fellow “fibro-warrior”.

ii. Crafting an illness Identity: It was observed that as part of emotional support these cohorts used communities to form illness identities using Facebook. E.g., fibromyalgia’s unofficial image representing users who suffer from this illness is the fibromyalgia butterfly. It was also observed that some form of this logo/badge was in their group and page information. Key informants shared: “Yep...it's our unofficial chart, just like the Spoon Theory. Not official (it's not) 100% accurate just like the stages (of fibromyalgia)” (Facebook09). The informant was referring to “the spoon theory” a blog post adopted by chronically ill individuals on social media. This theory uses the metaphor of spoons to discuss energy limitations chronically ill adults face when dealing with daily life.

iii. Building relationships (giving and receiving social support): Key informants shared that connections formed through these technologies served as a buffer against isolation from living with a physically debilitating chronic illness and the shame of sharing daily challenges faced with friends/family members who might not understand their conditions. Key informants reported that they are able to gain emotional support from peers who understand their physical, mental and emotional condition. Several relationships transcending the virtual space developed through these groups became intimate relationships e.g. friendships and romantic relationships. Some online friendships formed in the groups led to offline interactions e.g. face-to-face meetings, becoming pen pals and even sending and receiving gifts from those met online: “I send birthday cards, letters of encouragement, and talk with people (I met through the group) on the phone” (Facebook07). Some connections became romantic, as one informant explains: “Yes, I met my fiancé in this group. We started talking in
the group, then private message, and then talked on the phone, now 4 years later we live together.” (Facebook08).

3. Financial/Monetary support

It was observed that a small number (2) these cohorts had engaged in financial support. One informant recounts an experience of helping a member in need:

“One of the members in one of the groups lost her home to I think it was flood and there was the idea of selling t-shirts to help with the family's expenses and I purchased one...I think they also did a Go fund me too.” (Facebook10)

While another key informant shares her experience of selling a book about fibromyalgia, although she does not actively promote it on the group:

“My first chapter is dedicated to providing evidence- research that fibro is real. I have done 2 radio interviews, a few book signings and plan spoke at a conference oops- plan on doing more book signings. I spoke at a Women’s Christian conference in December.” (Facebook07).

7.3.3 Effects of the Facebook environment on appropriation for illness management

It was observed that the environment facilitated by Facebook also allowed the selective admission of members into these communities, while also screening prospective members, ensuring they have legitimate profiles and intentions to join. This is moderated to some extent by features built into Facebook, as an informant explains: “When it comes to being closed members need to be approved but nowadays (scammers) are getting smarter, they make their selling posts friends only and send out 5 - 10 friends requests a day.” (Facebook04). In contrast, the Facebook page is free to view and follow for anyone with a Facebook account. However, posts/comments from followers are monitored and must be approved by page owners to remain on the page without being deleted. The relevant sub-themes are discussed below:

1. Accessibility and ease of use of Facebook

Most key informants were unable to say which technology features they used most often; however, they found them valuable because of what they could accomplish through appropriation: “Facebook is a medium available to everyone with basic Internet skills, so is known about and is readily accessible for most people.”
Facebook features did not seem visible to key informants, yet the effects of technology could be seen through their actions such as reading others’ posts, reacting, sharing, commenting and saving posts.

2. **Community of similar others and evolving roles**

Key informants shared that a major motivation for their use of Facebook involved the opportunity to access a global community of similar others. In addition, key informants shared that membership to these communities involves rigorous screening, to enable only genuine profiles access to these communities. It was observed that members have roles which may evolve over time and members who contribute to building a positive group atmosphere are often asked to join the team’s administrative group. In some instances, members volunteer if they believe current administrative processes of the group could be improved as one informant shared his experience: “*Original role, reader, the other admin who did most of the posting has gotten busy so I messaged her and became one of the admins. Current role, leader, I would describe myself as one of the admins.*” (Facebook04).

i. **Community rules and norms**: Key informants shared that the administrators (admins) establish norms and set the tone for the group. However, as community membership grows, norms are imposed by the community themselves who report violations to the admins. We also noticed incidents where members of this community left to form their own, in some cases, groups splintered, and members left forming their own groups, often taking along other group members. We noticed new splintered group attempts to draw on prior community members as new ones, as one informant explained: “*There have been other new groups start up and branch off but they have a narrower focus (like religion) that I'm not interested in.*” (Facebook05).

ii. **Community splintering**: A few informants shared how these communities sometimes broke up and members left to form their own new Facebook group, in some cases taking along other members of the older group. One informant explains: “*Yes, I was an admin in the FAKS group- but stepped down because I had other obligations for my book and I knew I was starting my own group.*” (Facebook07)

It appears that these new splintered groups attempt to draw on the community of the previous group as members. The excerpt below indicates that members within the old groups have been invited to join the off-shoot groups: “*There have been other new*
groups start up and branch off but they have a narrower focus (like religion) that I'm not interested in.” (Facebook05).

### 7.3.4 Summary of findings

This section provides an outline to summarize key findings from the Facebook study.

- Process of appropriating Facebook for illness management
  - Lurking as passive learning
  - Liking and reacting to show support
  - Posting and commenting to exchange information
  - Borderless technology appropriation

- Individual incentives for adoption and continued use of Facebook for chronic illness management
  - Information support: Making sense of fibromyalgia and raising awareness
    - Increased understanding and illness advocacy
    - Communal filtering through misinformation/spam
    - Applying shared coping mechanisms
  - Emotional support exchanges: coping with the burden of fibromyalgia
    - Dealing with illness stigma as a community
    - Crafting an illness Identity
    - Building relationships (giving and receiving social support)
  - Financial/Monetary support

- Effects of the Facebook environment on appropriation for illness management
  - Accessibility and ease of use of Facebook
  - Community of similar others and evolving roles
    - Community rules and norms
    - Community splintering
The next section provides a discussion of key findings from the Facebook study and outlines the identified affordances from this case.

7.4 DISCUSSION

This section discusses findings from the Facebook case study to expand cumulative findings (see Chapters 4, 5 and 6) regarding the process of appropriation of SMTs by chronically ill adults. A deeper discussion of these findings in relation to the practice lens and related literature is provided in Chapter 9.

Process of appropriating Facebook for illness management by chronically ill cohorts

First, appropriation in this context was voluntary and in line with the primary purpose of Facebook i.e. networking with friends and family. However, joining specific fibromyalgia communities on the site was triggered either by being diagnosed with fibromyalgia or; suspecting a fibromyalgia diagnosis. Each of these patterns of appropriation for illness management has a purpose within these individual’s illness management practices: Lurking gives these cohorts an opportunity to familiarize themselves with their community, learn norms and gain information from others’ posts while retaining a semblance of privacy. Lurkers formed a larger majority of the members of the community and this action seemed to allow these cohorts to engage with the community while requiring minimal effort. This finding confirms previous scholars assessment of lurking as an active learning phase allowing users to passively gain information support while retaining privacy (Han et al. 2014). Perhaps in the context of chronic illness, lurking may be helpful for these cohorts who also experience emotional distress and chronic fatigue because of fibromyalgia. Some users may progress past the lurking phase and become more active members of the community, but a larger number choose to passively participate in these communities through lurking. Furthermore, these findings also demonstrate that users may vacillate between lurking and active participation depending on their needs and emotional capacity at the time. Liking and reacting gave these cohorts an opportunity to demonstrate support using those emotive features. This finding supports previous studies that suggest liking and reacting serves to demonstrate support and acknowledgement of posts (Wohn et al. 2016). Furthermore, as indicated in the “Liking and reacting to show support” subtheme, this action is important to the community because it serves to reassure posters and encourage continued interaction within the community. Posting and
commenting were used for either seeking treatment information options, to ‘rant’ or to share emotionally charged experiences. In general, most of the posts were made as an opportunity to vent about the lack of understanding these cohorts faced in their real lives. This was interesting because, during the study, informants had been questioned concerning to what extent they discussed fibromyalgia on their personal profiles, the majority indicated that they did not discuss this on their profiles because they did not want to seem to be constantly complaining. Some of the posts were also aimed to better understand how to manage their symptoms better or to validate their symptoms by comparing with others. For example, some members would make posts asking about the side effects of some of the medication they were taking for their illness and make decisions on continued use of these prescribed medications based on others experiences which were submitted as comments. Because these technologies are free to use and accessible, they are often adopted in tandem, in contrast to previous studies on appropriation which suggest that users may adopt/use one technology for one task. Some of our informants also used other social media technologies based on their different capabilities, treating these as part of a toolkit to better understand and manage their illness. Borderless appropriation of social media tools serves as an example of how individuals’ social media practices in the public space differs from the norm reported in previous studies (Yoo 2010). It seems that the free access and availability of numerous social media technologies allows users to appropriate various technologies using them as part of a toolkit to achieve various aspects of their goal.

Influences on Facebook appropriation for chronic illness management

This set of findings align with earlier research on the influences on social media appropriation for chronic illness: information support exchanges; emotional support appear to exert influence on appropriation of Facebook by key informants (Bodenheimer 2002; Merolli et al. 2013b; Pousti et al. 2014).

In addition, it seems that information support exchanges had significantly influenced health-related decisions made by these cohorts as indicated in the information support subtheme. Because they often discussed their current treatment regimens through posting and offered honest evaluations of their experiences on various medications, this served to educate other members. Also, findings demonstrate through the information support theme that our informants enabled a better understanding of illness, which enabled individuals to advocate for themselves with
general practitioners and others. For example, some of the information shared also included tactics and hints to successfully apply for disability pension, especially since most of these cohorts were unable to work full-time because of fibromyalgia. This finding supports claims that social media technologies such as Facebook could serve as viable sources of health-related information (Rozenblum and Bates 2013). This present study also revealed that although the community collectively attempted to protect themselves from misinformation, they still had numerous encounters with spammers and scammers who tried to take advantage of this vulnerable community. Combating these tactics proved challenging for the administrators/moderators of the group because members were emotionally fragile due to the daily challenge of living with fibromyalgia and the spammers also made use of private messaging and other Facebook features such as limiting the audience of the post to members who they had already become friends with, therefore admins were only aware of these activities when members reported to them.

Similar to previous studies, key informants had experienced emotional benefits from appropriation of Facebook and considered it as a safe place to interact with a group of similar others (Merolli et al. 2013). Through the exchange of emotional support, members were able to feel safe, understood and validated. These exchanges took place virtually at first, through posting, commenting, messaging and so on. Furthermore, for some cohorts, the exchange of emotional support helped them gain friends and romantic partners which was challenging in the real world due to the physical limitations of fibromyalgia. Yet, while exchanges of emotional support could serve as a positive influence that encouraged building relationships and dealing with illness stigma, it also negatively impacted these cohorts due to the barrage of emotionally charged posts in this community. This case study showed that some of the posts were rants about difficulties other members were facing such as conflicts and relationship breakdowns with family, friends and their GPs due to not being believed or understood about the symptoms they were experiencing. Some other posts were even more disturbing- for example, there were multiple posts about potential suicides asking for emotional help or posting to say goodbye. The Facebook notification and newsfeed served to constantly display all the most recent posts made in these groups leading to constant streams of negative emotional content which caused others in the community who read these posts to feel depressed and overwhelmed. Consequently,
emotional support could result in emotional overload serving as a barrier to appropriation (Maier et al. 2015). Especially since these cohorts already experience emotional effects from fibromyalgia; like depression and anxiety due to their illness. Overall, these influences led to variations in the patterns of appropriation as some members responded by posting and commenting to request that others be more positive, liking and reacting to the posts to show either support or annoyance (using the angry face emoticon), or in some cases members either changed the notifications they got from the group, effectively putting the group on mute to take a break from the barrage of posts.

When asked which features of Facebook were used and how, some informants stated that they did not make use of any, which was directly contradictory to the researcher’s observations; especially since the semi-structured interviews were conducted through Facebook messenger. A possible explanation for this “feature-blindness” could be that Facebook features had disappeared from view as a result of familiarity with the site and similar social media technologies. This finding aligns with technology appropriation literature which suggests that after encountering a technology, it disappears from view as users engage more frequently with it (Mendoza et al. 2010). Previous studies also suggest familiarity with similar technologies could result in users developing mental frames that influence their appropriation outcomes due to an inherited understanding of similar technology artefacts and their use (Treem et al. 2015). Moreover, Facebook became a virtual safe place for these cohorts enabling interactions with peers who understood them in a separate space from their profile pages (Mendoza et al. 2010; Riemer and R. B. Johnston 2012). They could take refuge in these spaces with similar others to participate in these spaces either passively through lurking, tentatively through liking and reacting or more actively through posting and commenting without fear of stigma. Through community membership, these cohorts could develop a positive illness identity and so gain a more positive outlook on their illness. This shared ‘fibro-warrior’ identity encouraged a sense of control, empowerment and belonging, in addition to created shared understanding for coping with their illness through concepts like: spoon theory; fibro butterfly, stages of fibro. Overall, findings indicate that membership, policies, norms and roles were informally negotiated by members of the community and in a constant state of flux. Moreover, these groups were not stable; with changes in group policies or
disagreements in the community causing members to leave to form their own groups centred on their personal beliefs or disappropriate those spaces entirely.

The next section provides outlines various affordances identified by the researcher during the case study.

**Identified affordances which enable or disrupt positive illness outcomes**

Because of the interactions between the motivations of the study cohorts and the influences and constraining structures exerted on these cohorts by the environment formed on the Facebook site, the following key affordances were observed.

Identified affordances which enable appropriation of Facebook by chronically ill adults:

- **Compartmentalization**: This affordance allowed key informants to operate in each privacy in groups of other chronically ill cohorts.

- **Reputation**: Enables the user to know the standing of other users due to the tags attached by the Facebook SMT to each member in the groups based on how long they have been in the group.

- **Storytelling**: It was observed that these cohorts were able to share detailed stories about issues of concern with others in the group

- **Considered participation**: This allowed members to remain in the SMT environment without any pressure to interact with others.

- **Persistence**: This allows new users to interact with and benefit from content long after it has been discussed by other members of the online community. Sometimes, this content may be discussing rules and community guidelines or information resources.

- **Sensemaking**: The sensemaking affordance refers to the extent to which the user is able to utilize the tool in making sense of their symptoms. This affordance may be realized before or after the official medical diagnosis by healthcare professionals.

Identified constraint which disrupts appropriation of Facebook by chronically ill adults:
- **Emotional overload**: Due to the constant deluge of notifications and updates of members posts on the group feed, this served as a constraint. Some key informants noted the emotional overload they experienced as a consequence of participation on Facebook.

The next chapter presents the cross-case synthesis of findings from the multiple case study.
Chapter 8: Cross-case synthesis

INTRODUCTION

This chapter aims to deepen understanding and explanation of social media appropriation by chronically ill adults through a synthesis of findings from the four case studies presented in Chapters: 4, 5, 6 and 7. Accordingly, this chapter condenses the key findings from the multiple case studies and illustrates the extent to which concepts found regarding the four case studies are similar or unique (Miles et al. 2014). The following Chapter (Chapter 9) critically evaluates findings from these case studies and presents a process model and framework.

8.1 CROSS-CASE BACKGROUND

There were 42 key informants in total and these cohorts participated in online interviews with the researcher and permitted observation of their activities related to illness management for the duration of the study. Based on the categorization specified in Chapter 2 Section 4.1, the key characteristics of each case are described below to provide a background to the following sections:

- **Facebook**: Facebook was found to provide a mix of capabilities that supported the key informants’ need for presence, connection, entertainment and conversations through technical features such as groups, contacts tab and the activity stream (news feed) that served as mechanisms that support these needs. The key informants of the Facebook case were all members of fibromyalgia groups and followed fibromyalgia pages which gave them access to others in similar circumstances with whom they could interact.

- **Instagram**: At first glance, image sharing sites such as Instagram present functionality to the user that supports the display of a public self with a lower emphasis on connections and a higher focus on reputation and building of a public image/identity with a high emphasis on image. The popular technological mechanisms used by key informants seemed to be the sharing images, searching, hashtagging these images and creating sub-profiles for illness management purposes. Key informants indicated that these mechanisms
served to support ad-hoc community formation around their posts, giving access to a community of similar others.

- **YouTube**: Overall, key informants shared that YouTube *enables a high level of self-disclosure* through the video blogging activities that users carry out on the SMT. The study key informants were all YouTubers who considered themselves central parts of the chronic illness community of YouTube and the structure of the site allowed ad-hoc community formation around video uploads. Further, users could interact with a video upload through features such as like or dislike of a video clip, subscribing and viewing.

- **Reddit**: Reddit appeared to focus on *emphasizing conversations, groups and reputation* through mechanisms such as subreddits, posts and a Karma point system which is allocated to the user based on her/his posts and comments on the SMT (see Chapter 4 Section 4.1.1). Key informants indicated that the Reddit SMT allowed for greater anonymity within these groups because the profiles did not require a high level of personalization and in some cases did not require a link with other social technologies the user may have adopted, for example, Reddit did not require a verified email account prior to adoption.

Each SMT had a range of technical capabilities built in to support the needs of their user base; but there were a few features that were similarly implemented across all SMTs such as: newsfeed; content recommendation; content publication; integration with other sites through social plugins; discussion capabilities through comments and postings; and gamification mechanisms. To provide an initial classification of the four SMT tools that served as case study sites, a combination of honeycomb framework (Kietzmann et al. 2011) and uses and gratifications theory (Katz et al. 1973; Smock et al. 2011) are combined as a lens to identify key concepts based on the core features and capabilities of each SMT. Table 8.1 below presents the core concepts derived from technology analysis of the included SMTs in the present study (Refer to Chapter 3, Section 3.7.1 for more on the use of physical artefacts as data in this thesis). In the following sections of this chapter, the four cases will be referred to as: C1 (Reddit); C2 (YouTube); C3 (Instagram) and; C4 (Facebook).

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12 Selected findings from this case were presented in a full research paper at Australasian conference of information systems (ACIS) 2016
## Table 8.1 Technology features comparison across cases

<table>
<thead>
<tr>
<th>Concept</th>
<th>Features</th>
<th>Explanation</th>
<th>C1</th>
<th>C2</th>
<th>C3</th>
<th>C4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships</td>
<td>News/Activity Feed</td>
<td>A news feed keeps the user updated on the actions of each of the other members of the user’s network.</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Event Creation</td>
<td>This feature allows users to create social events and generate a virtual calendar which allows participation in the event by other users in the selected network.</td>
<td></td>
<td>❌</td>
<td>❌</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Social Groups</td>
<td>This function allows the creation of designated spaces for users to congregate and interact with each other over a shared interest, for instance, Reddit subreddit.</td>
<td>✔️</td>
<td>❌</td>
<td>❌</td>
<td>✔️</td>
</tr>
<tr>
<td>Entertainment</td>
<td>Content Recommendation</td>
<td>This feature generates a list of posts that might interest the user which have been curated and suggested based on the user’s activities on these sites.</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Entertainment/Games/Gamification mechanisms</td>
<td>These tools may incorporate some gaming systems or gamification mechanisms such as follower count on Facebook and Instagram to incentivize users to do more on the platform.</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Sharing with others</td>
<td>Content publication</td>
<td>This allows users to publish content that is visible to 1-n members of their selected network depending on each platform’s broadcast privacy capabilities.</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>File Sharing/Manipulation</td>
<td>This allows the user to upload share and manipulate files to the other members of their network.</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Search</td>
<td>Allows the user to search within the platform for a specified term or related terms.</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Conversations</td>
<td>Posts/Comments/Discussions</td>
<td>This feature allows users create posts or comment on posts and carry out discussions on any topic.</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Messaging services</td>
<td>This allows the user to communicate with 1-n respondents in a private communication channel.</td>
<td>✔️</td>
<td>❌</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Reactions</td>
<td>Allows a user to communicate with other users through a pre-set library of emoticons; such as thumbs up for like or a heart emoticon for love.</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Call Conferencing</td>
<td>Allows the users to make internet calls to others on their network, the functionalities provided by each platform could range from video calls to audio-only calls.</td>
<td>❌</td>
<td>❌</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Identity</td>
<td>User Profile</td>
<td>This allows the user to create a public persona through which other members of the network identify him.</td>
<td>✔️</td>
<td>✔️</td>
<td>❌</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Personalization</td>
<td>Allows the user to customize the way content is displayed to him or the look and feel of his public profile.</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Social Plugins</td>
<td>This group of features enable users to share external content on these social media platforms. Social plugins enable users to utilize one profile across a wide variety of sites that they visit by allowing them to sign in and use their existing profiles to interact with external sites.</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Privacy settings</td>
<td>Allows the users to take measures to protect themselves and their content from being displayed to unauthorized users or the public</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Tagging and Hash-tagging</td>
<td>This enables users to add special keywords to the content they post on these sites enabling other users to search for that content by its tag or hashtag.</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
</tbody>
</table>

Legend: C1=Reddit; C2=YouTube; C3=Instagram; C4=Facebook
The next section provides a comparison of key findings for each case based on three main dimensions: a) individual incentives for adoption and continued use; b) patterns of appropriation and c) emergent influences on appropriation.

8.2 GENERAL FINDINGS ACROSS ALL CASES

The concepts compared in this section relate to three aspects relating to the process for appropriation of SMTs for chronic illness management, personal factors that support or discourage appropriation of SMTs for chronic illness management and the factors relating to the SMT environment based on findings in Chapters 4-7. First, Section 8.2.1 outlines the common concepts found in the study that relate to the process of appropriation.

8.2.1 Process of appropriation: common concepts

Firstly, all informants unanimously reported that they adopted the SMTs used in this research as part of their toolkit for self-management of fibromyalgia. Moreover, these informants seemed to distinguish adoption for illness management, from adoption for hedonic purposes in line with the main purpose of these SMTs. There are variations to how this antecedent played out for each case; for instance: most informants on C3 and C4 already had accounts on these sites prior to appropriation for illness management specific appropriation. Yet, on C1, most informants indicated that their adoption was primarily for illness management purposes. Conversely, the findings from C2 were mixed, with most informants revealing a certain level of appropriation before applying YouTube for illness management. Most informants from C1-C4 made use of these SMTs with frequency ranging from multiple times a day to several times a week. This section summarizes the ways the four different technologies included in the study were appropriated across the four user cohorts.

To further classify the processes of appropriation across all cases, the terms “tentative appropriation pattern”, “reactive appropriation pattern” and “proactive appropriation pattern” are denoted to categorize the types of appropriation activities carried out by these cohorts on each social media tool (within the environment provided by the tool): 1) Tentative pattern refer to those activities where the user can view and interact with the SMT, but retains a level of disengagement or disentanglement from the community; 2) Reactive pattern refer to activities where the user engages based on actions by others in the community and 3); Proactive pattern
refers to those activities where the user is at the forefront of activities within the SMT. Moreover, there are four other concepts related to processes of appropriation which denote the frequency of use, “parallel /borderless appropriation of multiple SMTs” and “adaptive appropriation pattern” undertaken by key informants to bring these SMTs into their illness management practice. Majority of the adaptive actions are carried out by informants in response to either the technology feature or policies imposed on these cohorts by the SMT. Finally, disappropriation may occur in response to numerous factors such as negative outcomes; or negative influences which may impede these vulnerable cohorts from accomplishing their illness management goals on each SMT. Specific examples of these concepts and their occurrence across each case include:

1. **Tentative appropriation pattern**: Apart from C4, most informants in the other three cases shared that they had taken a passive/tentative stance at first for appropriating these SMTs, they practiced lurking as the first step to appropriation. Key informants shared that practiced lurking initially reading through posts on the tools to familiarize themselves with group norms. On C4, 1 key informant had not progressed past lurking although she engaged with the community frequently. In addition, key informants from C2 and C1 also displayed tentative appropriation patterns.

2. **Reactive appropriation pattern**: Reactive appropriation patterns were observed in all cases but based on the technical capability/features of each SMT, the emergence of reactive actions varied. For instance, on C1, key informants reacted by upvoting or downvoting content to show support while on C2 key informants reacted by liking or favouring video uploads by others in the community.

3. **Proactive appropriation pattern**: All informants in C2 and C3 had reported proactive appropriation patterns although these were found at different levels across all 4 cases. Some key informants in C1 and C4 also displayed proactive appropriation patterns which involved actions such as posting and commenting on posts.

4. **Adaptive appropriation pattern**: Adaptive appropriation patterns were found in 2 cases: C1 and C2. An example of this pattern was observed through key informants who reported that they made use of browser plugins like the Reddit
enhancement suite to add desired functionality to their experience of C1. While in C2, these adaptive patterns were typically intended to work around limitations that arose either because of the features of C2 or to bypass restrictions imposed by the technology policy of C2. For example, using other social media tools to notify viewers about newly uploaded videos or to chat with others from YouTube or making use of patreon.com to accept donations from subscribers since they did not achieve the metrics set by YouTube to allow them to gain financial benefits from their YouTubing practice.

5. **Parallel appropriation of multiple SMTs**: Parallel appropriation was observed at different levels across all 4 cases. Apart from C4, key informants from the other three cases shared that they also had appropriated other SMTs for their illness management purposes such as Tumblr. This was especially notable in C2 but occurred to a lesser extent in C1.

### 8.2.2 Personal factors that influence appropriation of SMTs for chronic illness management

Most informants revealed that they had personal reasons for appropriating these SMTs, which include seeking and offering: Information to cope with fibromyalgia and seeking to participate in emotional supportive exchanges only a few sought financial benefits from these exchanges and the bulk of informants who reported this goal were found on C2, C3 had 2 informant seeking monetary exchanges and C4 had 1 (see Table 8.2, below).

**Information support**: Information support concepts were found in all four cases with sub-concepts appearing in all 4 cases which include collective sensemaking, applying shared coping mechanisms or illness advocacy indicated in Table 8.2 below.

Among the concepts related to the information support idea were:

- **Collective sensemaking**: Key informants across all cases (C1-C4) were found to engage in collective sensemaking about their illness symptoms and treatment options. These sensemaking activities took place through posts and comments on all four SMTs and other users on the site would contribute based on their personal experiences to aid those with problems to determine solutions.

- **Applying shared coping mechanisms**: Access to the coping practices of peers appeared to be act as an incentive for appropriation for key informants in C2, C3 and
C4 who shared that they often applied coping strategies recommended by their peers on the SMT in their personal illness management practices, while on C1, it appeared that informants were less interested in these coping strategies from peers on Reddit.

- **Illness advocacy:** It appeared that informants on all four cases (C1-C4) made use of the information obtained from peers to better advocate for their care with their GPs or rheumatologists across all cases. Therefore, shared information served as a mechanism to empower study informants to advocate for themselves both with their doctors and on SMTs through events like fibromyalgia awareness days, or through wearing and promoting the colour purple.
<table>
<thead>
<tr>
<th>Main concept</th>
<th>Sub-concept</th>
<th>C1</th>
<th>C2</th>
<th>C3</th>
<th>C4</th>
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<td>Information support exchanges</td>
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<td>Applying shared coping mechanisms</td>
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<td>Activism to spread awareness about fibromyalgia</td>
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<td>Building borderless relationships</td>
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<td>Financial/ Monetary support exchanges</td>
<td>Building a brand</td>
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Legend: C1=Reddit; C2=YouTube; C3=Instagram; C4=Facebook
• **Activism to spread awareness about fibromyalgia**: Key informants on C2, C3 and C4 shared that they were motivated to appropriate those specific SMTs to raise awareness about fibromyalgia. For instance, informants made posts, shared memes etc to increase the visibility of fibromyalgia. In contrast, for informants from C1, advocacy did not appear to act as an incentive.

**Emotional support exchanges**: nine emotional support exchanges were identified across the four cases with only two emotional support elements (Dealing with illness stigma and Building of borderless relationships) consistent across all four cases. Among the sub-concepts induced from the emotional support idea were:

- **Dealing with illness stigma**: key informants in cases C1-C4 shared that these SMTs served to aid in dealing with the stigma of fibromyalgia.

- **Crafting an illness identity/Creating shared terminologies to craft shared identity**: This idea was supported on C2, C3 and C4 but not found on C1.

- **Building borderless relationships**: Evidence of this was found mostly in C4, C2 and C3, while it was not observed on C1.

- **Emotional overload**: Emotional overload was observed on C1 and C4, as a consequence of membership to a larger community of chronically ill individuals. Emotional overload appeared as a consequence of the SMT technology features.

- **Coping with loneliness from chronic illness**: Study informants on C2, C3 and C4 appeared to use SMTs as a means to deal with isolation. This finding was not observed in C1.

- **Therapeutic exchanges to combat isolation**: It appeared that study informants on C2 and C3 considered their exchanges with others on the SMTs to be a therapeutic mechanism that alleviates some of the isolation of chronic illness.

**Financial/ Monetary support exchanges**: A few key informants reported that they used these SMTs in hopes of obtaining financial support. Further, most informants who shared their hopes for monetary benefit were on C2 although there were a few users on C3 who indicated financial motivations, C4 in contrast only had 1 informant who hoped to obtain a financial benefit. Similarly, key informants in C1 did not indicate monetary support to be an anticipated benefit from appropriation of Reddit. Specific examples include:
• **Monetization**: All key informants from the C2 hoped to gain financial benefits by making use of the monetization mechanisms available on the site such as ad-sense and other similar features, but they all reported difficulty due to not meeting the monetization criteria set up by the SMT (YouTube).

• **Building a brand/Creating a business**: Key informants on C2 shared that they were aimed to build a social media presence and a brand with the aim to generate a source of income. A few informants on C3 also aimed to build businesses through their use of the SMT. These branding attempts involved actions such as: using the same profile name across all social media; selling t-shirts and mugs that feature images or text related to fibromyalgia. Conversely, key informants on C1 and C4 did not appear to be interested in building a brand or business through the SMT.

### 8.2.3 Influences of SMT environment on appropriation

Across all 4 cases, key informants shared that these SMTs acted as online spaces where they could interact with others with the same illness across time-zones, disparate geography and overcoming the physical limitations imposed by fibromyalgia. As such, there were some key issues that impacted appropriation related to the technology features and community of similar others. In C4, membership was subject to screening and assessment, to access the community for the Facebook groups, while the Facebook page allows anyone with a Facebook account to follow and be part of that community. In contrast, C1, C2 and C3 were more easily accessible to differing extents by anyone with an internet capable media device such as a laptop, a tablet device or a smartphone. The relevant influences are discussed below:

i. **Technology features**: C1 was designed to resemble a discussion board and key informants indicated that this format/structure gave them a sense of comfort, alleviating any pressure to interact with others. While informants on C2 reported that adopting YouTube was challenging to them because the features were difficult to use although the community helped them understand what they required to start vlogging. Key informants on C3, indicated the influence of technology features which they considered easy to use, although some other features were more apparent to them over time on Instagram. Similar to C3, key informants on C4 shared that they found
Facebook very easy to use but when prompted to share which features they used the most, struggled to mention specific features of Facebook.

- **Anonymity and privacy:** Profiles on C1 were quite de-personalized and so, key informants reported that they retained a sense on anonymity which allowed a sense of freedom while interacting on the site. Moreover, C1 also allowed users to customize their profiles or posts with taglines or “flairs” as indicated in Figure 8.1 below which gave them the ability to customize their presence in the subreddit. Technology features of C2 were more focused on allowing users to easily find others based on their search criteria. Also, key informants on C2 had their channel description, videos and contact information publicly accessible to anyone with internet access. It was observed that key informants on C3 sometimes made use of the sub-profile feature of Instagram to compartmentalize their illness from daily life, while C4 allowed users to make their profile pages private, furthermore the groups the researcher recruited from were all closed and private groups based on the privacy settings provided by Facebook.

![Figure 8.1 Sample Reddit profile](image)

- **Ease of use:** key informants on C1, C3 and C4 indicated that they found these SMTs easy to use which contrasted with the accounts from most key informants on C2 who shared that YouTube was challenging to use, yet key informants on C2 noted that they learned from tutorial videos posted by others on the SMT on how to create content.

- **Constant/Perpetual supportive environment:** Key informants from C1, C3 and C4 discussed how they found these SMTs provided them with constant access to others who could relate with their illness management challenges. Most informants stated that they always had access to others online. Moreover, it was observed that C1, C3 and C4 use features which signal the availability
of other members of the community and because of the geographically dispersed nature of these cohorts, key informants noted that there was always someone online to talk to. In contrast, Key informants on C2 reported that the messaging and other features of YouTube were known to be unreliable, but they reported using other SMTs like Instagram or Twitter to gain a constant supportive environment.

- **Taglines and personalization**: It was observed that C1, C2 and C3 allowed key informants to personalize their presence to differing levels: C1 allowed users to have taglines in their profile signatures which could be specified for each subreddit, so they could either add more information about themselves or choose a witty phrase. C2 had the profile page where the user could upload a banner, add descriptions about them and links to their other social media channels, creating a customized presence on YouTube; Similarly, C3 also allowed personalization through creating multiple profiles for one account, so key informants could “change persona” based on which profile they chose to use. Moreover, these sub-profiles on C3 also allowed users to post a description to inform others about what that specific profile was about. C4 appeared to support that to a lesser extent, although the user profiles on Facebook could be personalized, there did not appear to be any further customization possible for the user as they moved across various spaces on the site.

- **Accessibility and openness**: Key informants on C1 and C2 in particular stated that these SMTs were accessible and open to view for anyone, most informants on these two cases reported that this influenced their appropriation because they were able to consume content and lurk before they created accounts and joined Reddit and YouTube. In contrast, this was not mentioned to the same extent on C3 where key informants reported that they were influenced because of the accessibility and high availability of Instagram. Further, only 2 informants on C4 mentioned accessibility as an influence on their appropriation of Facebook.

i. **Community**: It was observed across all 4 cases that these SMTs supported the formation of virtual communities of similar others with fibromyalgia. Sites like C1 and C4, supported explicit or M to M group formations around topics of interest, while
sites like C2 and C3 supported ad-hoc community formation around content or hashtags (C3). The related notions are compared below:

- **Community norms and rules**: It was observed that C1 and C4 communities had explicitly written rules for interaction which were intended to deter undesirable behaviours. For instance, C1 banned actions like trolling, posting spam content and asking for diagnosis; while C4 banned actions like trolling; posting spam content; scamming or soliciting funds; use of harsh language or curse words and; selling products. Likewise, key informants on C2 reported that the fibromyalgia community on YouTube had implicit rules which also were aimed to deter similar activities. Moreover, these rules were often enforced by members of the community regardless of their roles, particularly in the cases of C2 and C4. On C2 commenters on the videos enforced these rules by reporting those types of comments and acted to police the behaviours of other members of this ad-hoc group with the intention of protecting key informants conversely, this was not observed on C3.

- **Ad hoc Community formation**: Ad-hoc community formation was observed in C2 and C4, moreover, informants reported that they interacted with other members of the community around content such as videos and uploaded photos in the commenting section of the content. Also, key informants on C3 reported that they also gathered around related hashtags such as: #spoonie or #fibrowarrior which supported community formation around their hash-tagged topics of interest, which they could locate by exploring or searching on Instagram; further, they indicated that these hashtags acted as calling cards to find others with fibromyalgia on Instagram.

- **Community roles**: Key informants on C1, C2 and C4 reported that these communities had roles among the members based on their contributions. For instance, on C1 and C4 there were explicit roles like admin, moderator and it was also observed that there was a hierarchy among other members of the community based on their participation. This was not observed on C3. On C2, key informants were considered central members of the community based on their regularly scheduled uploads which were expected to follow certain schedules.
8.3 UNIQUE FINDINGS SPECIFIC TO INDIVIDUAL CASES

The findings presented in this section concern unique concepts that were observed in only one case and include:

8.3.1 Reddit case study

- **Gender relations and r/fibromyalgia as a feminine space**: This was a community concept only observed in C1 and reported by a few key informants in C1. Key informants indicated that the nature of fibromyalgia and associated imagery were considered to be feminine. Further, an informant on C1 reported that this sometimes causes arguments in this community by male members who felt left out due to this.

8.3.2 YouTube case study

- **Self-presentation as therapy**: This was a sub-concept under emotional support that was observed only in C2. Key informants on C2 shared that they considered creating and presenting themselves on YouTube to be therapeutic particularly because they could be authentic and vulnerable.

- **Building workarounds for YouTube features**: This was a notion under the process of appropriation that was observed only in C2. It was observed and reported by most key informants on C2 that they had to construct workarounds to overcome difficulties they experienced while carrying out tasks related to YouTubing. For instance, they had to make use of other technologies to carry out tasks like editing video content or communicating with others on YouTube. It was observed that these technologies ranged from free software to more expensive professional video editing tools were applied to carry out those tasks.

- **Incorporating other technologies to support appropriation of YouTube**: Most key informants on C2 shared that they had to make use of other specialized technologies to carry out their YouTubing practice. For instance, some had to purchase cameras, tripods, lighting and other tools to produce high-quality video content.

- **Technology policies**: While all 4 SMTs had explicit usage guidelines and policies imposed by the companies providing access to these technologies, it was observed and reported by some key informants on C2 that the technology
policies of YouTube directly impacted their YouTubing practices. For instance, the policy on contentID constrained these cohorts to making use of either original, self-produced audio materials or to restrict their selection to the offerings in the creator studio library.

8.3.3 Instagram case study

- **Resistance to specific technology features**: This was only partially observed in C3, where only one informant shared their resistance to the go-live video streaming feature also, one other informant from C3 shared that she found that feature awkward sometimes.

8.3.4 Facebook case study

- **Communal filtering through misinformation/spam**: On C4 key informants reported and it was observed by the researcher that members of the community acted as a cohesive unit to weed out posts that shared false or harmful information. This filtering was conducted in the comment section, in addition, members notified the admin or moderator, who then took action by removing the posted content.

- **Community splintering**: This idea was only partially observed in C4, where members of the Facebook groups left to form their own, in some cases taking along other members of the group.

8.4 SUMMARY

This chapter has synthesized the results from the three case studies described in Chapters 4, 5, 6 and 7. The first facet concerns incentives to adopt and use these SMTs, the next topic concerns process of appropriation demonstrated by key informants, subsequently the third notion concerned influences from the technology and community are presented. Finally, the Chapter concluded with unique ideas that were derived across the 4 case studies.
Chapter 9: Discussion

INTRODUCTION

This Chapter mobilizes findings from Chapters 4 to 7 to advance theoretical insights on how chronically ill adults appropriate social media to understand and manage their illness. First, this Chapter proposes a new integrated process model to provide new insights pertaining to activities and influences involved in the appropriation of SMTs for chronically ill adults. Secondly, this Chapter develops a new framework that outlines factors that support or discourage social media appropriation by chronically ill adults. Finally, this Chapter outlines how technology features and structures of different SMTs enable or disrupt self-management of chronic illness based on findings in the previous Chapters (Refer to Chapter 4-8).

Section 9.1 revisits the fundamental MTA practice lens to evaluate confirmations and extensions derived from this multiple case study. This practice lens extends the original MTA with Social Support Theory (SST) and Theory of Affordances to provide an integrated model for social media appropriation in the context of chronic illness self-management.

Next, Section 9.2 provides a new integrated model to explain the processes and influential factors unique to social media appropriation by chronically ill adults. Section 9.3 outlines a new framework which focuses on factors that exert supporting or discouraging influences on appropriation of social media. After that, Section 9.4 presents a set of affordances provided by SMT features which enable or disrupt appropriation (see Section 9.4) in the social media context. Subsequently, Section 9.5 brings together the ten propositions that are derived from this work to address the research aim and provide an integrated view on appropriation of social media by chronically ill adults. This Chapter then concludes with a summary in Section 9.6.

9.1 EXTENSIONS TO THE MODEL OF TECHNOLOGY APPROPRIATION (MTA) IN THIS STUDY

The fundamental theory extended by this work is the Model of Technology Appropriation (MTA), a process model that describes phases of appropriation and factors identified as exerting negative or positive influences on appropriation of an IT artefact (Carroll et al. 2007; Mendoza et al. 2010). MTA was developed during a month-long study and was applied to investigate mobile phone appropriation by youth (Carroll 2004; Carroll et al. 2007). This study
also incorporates extensions to MTA provided by other scholars who have extended MTA to a defence context (Fidock et al. 2008; Fidock and Carroll 2006); and in an educational setting (Mendoza et al. 2010). Overall, these studies demonstrate the usefulness of MTA to explain the technology appropriation process and accompanying factors that serve to discourage or encourage appropriation of technology.

However, MTA has limited explanatory power for the social media context because it does not account for the unique characteristics of social media technologies in terms of the social aspects of SMTs. Further, the explanatory power of MTA is particularly limited in the context of appropriation of SMTs by chronically ill individuals, where emotional factors and illness-specific tasks play a significant role to discourage or encourage appropriation. Accordingly, this thesis at hand extended MTA with concepts from SST and the theory of affordances to derive theoretical insights on appropriation in the social media context by chronically ill adults.

To reiterate, SST suggests that chronically ill individuals (depending on their level of self-efficacy) participate in offline or online social interactions to exchange: emotional, information, social material and esteem support which aids their illness management practices (Bandura 1998; Barrera 1986; Huh et al. 2016; Lazarus 1993). Related studies in the context of chronic illness applied SST to highlight factors related to chronic illness management that drive adoption and use of SMTs. However, SST does not account for technological factors or the processes involved in appropriation of SMT for chronic illness management.

The present work also extends MTA with the theory of affordances which suggest that an IT artefact offers particular action possibilities depending on the user and their task (Gibson 1986; Majchrzak et al. 2013; Treem and Leonardi 2012). Furthermore, different SMTs have technology features/structures that might enable or disrupt the tasks of chronic illness management. Theory of affordances practice lens suggests that users may perceive the possibilities of actions available in a technology design as either constraining or enabling their tasks according to each individual’s social norms and beliefs (Bernardi 2016; Merolli et al. 2015). Related studies on social media had suggested that SMT affordances include self-presentation, narration, structure, flexibility, triggered attendance, flexibility, connection, adaptation, exploration, persistence, visibility, editability and metavoicing (Bernardi 2016; Majchrzak et al. 2013; Merolli et al. 2015; Treem and Leonardi 2012). (Refer to Chapter 2, Section 2.7.1 for a full explanation on the fundamental extension of MTA applied to this study).
9.1.1 Confirmation and extension of MTA

First, this present study confirms the basic premise of MTA with the two practice lenses: SST and theory of affordances. Our study agrees that appropriation is a process influenced by contextual positive or negative factors and depends on a user’s illness management task they aim to accomplish with a given technology. The following section outlines extensions to MTA from the present study.

Process of appropriation in MTA: MTA outlines three stages of SMT appropriation: initial encounter, evaluation and stable use. These appropriation stages are influenced by a variety of factors which are listed above in the preceding section while a user trials and adapts technology to their specific use context. Moreover, the MTA suggests that stability in the use of technology may only be temporary, further appropriation could still occur based on evolved influences and the user’s expectations from technology (Mendoza et al. 2010). Besides, the MTA study by Mendoza et al (2010) applied a longitudinal approach which showed that users may vacillate between re-entry and rejection during appropriation of technology. Further, according to Mendoza (2010), stable use could be a temporary phase because users may carry out further evaluations of the technology based on emerging events and their resulting need to further adapt technology to their practices. As a whole, MTA studies suggest three main phases of appropriation which are dynamic because a user may transition between stable use and evaluation or may re-enter the appropriation process after rejection based on changes in their expectations of technology (Mendoza et al. 2010).

Extending the MTA process of appropriation for SMTs in the present study: Our findings confirm the dynamic process of appropriation suggested by MTA. However, our findings underline the differences between the phases of the appropriation process in an SMT environment compared to the phases proposed in the original MTA (Carroll et al. 2007) and its extensions (Fidock et al. 2008; Mendoza et al. 2010). In this study, there was a clear argument to indicate that the processes of appropriation in a social media context differ because the structure of SMTs support unique appropriation processes of multiple SMTs and for a single SMT. In the present study it was observed that chronically ill individuals could engage in parallel appropriation of multiple SMTs because SMTs are free to use, accessible on multiple devices and have different core capabilities. Accordingly, chronically ill individuals could appropriate multiple SMTs as part of an illness management toolkit to support different illness management tasks. Moreover, the present study also found unique phases in the appropriation process of SMTs such as tentative, reactive, proactive and adaptive phases. Therefore, the
present study extends MTA by showcasing the unique appropriation processes for a social media context.

Also, the present study argues the process of appropriation of an SMT may be static if that specific phase is sufficient to support the illness management needs of adults with chronic illness. For instance, some informants suggested that they persisted in the tentative phase of single SMT appropriation which involved lurking because it allowed them to gain access to information, emotional support while remaining relatively anonymous in the SMT community. Further, findings from this present study agree with the notion of dynamic appropriation which posits that users may vacillate between the different appropriation phases (Mendoza et al. 2010; Orlikowski 2000). In the present study, this dynamic appropriation process was a consequence of the effects of technology features such as updates or based on their personal health conditions. (Refer to Section 9.2 and Figure 9.1 for a comprehensive discussion of social media appropriation processes for chronic illness found in this study).

**Positive and negative factors that influence appropriation in MTA:** According to MTA, appropriation of technology is influenced by several factors which act as filters when a user initially encounters the technology artefact termed ‘technology-as-designed’. MTA suggests that a number of factors support technology appropriation including: technology features, perceived usefulness, adaptability, ease of learning, access to training, relative advantage, purchase cost, fashion/style, familiarity and subjective norms (Carroll et al. 2007; Mendoza et al. 2010). MTA factors which discourage appropriation of technology include the lack of: ease of learning, adaptability, and integration of the technology. Still, MTA suggests that supportive factors serve to reinforce appropriation of a technology despite the presence of discouraging factors such as lack of: adaptation or ease of learning (Mendoza et al. 2010).

**Extending MTA with influential factors in the present study:** The study at hand confirms some influences identified in MTA (Carroll et al. 2007; Mendoza et al. 2010). For instance, our findings suggest that factors such as technology features, perceived usefulness, adaptability, purchase cost, familiarity and subjective norms serve as important supporting influences on appropriation of SMTs. However, the present study found no evidence for the influence of fashion/style, the relative advantage of using the technology and access to training.

Furthermore, my study contrasts with traditional appropriation studies because in an SMT environment, factors like subjective norm (Davis 1989; Mendoza et al. 2010) emerged through the SMT community norms and rules. In this study, the discouraging impact of lack of
ease of learning was only somewhat substantiated by the YouTube case, but the other three case studies did not indicate the ease of learning as an influential factor on appropriation of SMTs. Similar to the proposition of MTA, although lack of ease of learning was a discouraging influence on appropriation of YouTube, its effect was mitigated by its positive supporting factors that reinforced appropriation such as the perceived value of YouTube. In the present study, factors found to exert a negative discouraging influence on appropriation of SMTs include spamming, scamming, trolling, complicated technology features, community breakdown/splintering and restrictive technology policies.

The present study extends MTA to include aspects of social support theory (SST) because of the emotional impacts of chronic illness and because chronic illness management is an ongoing daily task. Moreover, recent work on technology appropriation advocates a renewed focus attention to the emotional factors that might influence appropriation of technology artefacts in the healthcare context (Mendoza et al. 2013). This study confirms the broad concepts of SST as personal illness specific factors that influence appropriation of SMTs. For instance, the study supports the influence of social, emotional, financial/material and information support. Yet, the present study suggests that social and esteem support were found to be part of emotional support. This study found some support for the influence of financial factors through building a brand and monetization on two SMTs (YouTube and Instagram). On the Facebook case, financial support was partially observed through information support because chronically ill adults shared information on how to obtain access to disability pension schemes and donated through gofundme.com to members who experienced hardships. Financial support was not observed to influence appropriation of Reddit.

This study also suggests that SST broad concepts of information, emotional and financial support comprise several other mechanisms that encourage or discourage appropriation of SMT tools by chronically ill adults. For instance, our findings unpack information support to illustrate the influence of sub-concepts such as collective sensemaking, access to shared coping mechanisms, illness advocacy and activism. Similarly, emotional support exchanges also involve illness stigma, loneliness and isolation which positively influence appropriation of SMTs. Further, this study suggests factors unique to chronic illness and social media environments such as loneliness, isolation, loss of identity, illness advocacy, stigma and community may influence appropriation in this context. The present study also suggests that factors like emotional overload, trolling, scamming/misinformation, community splintering and spam had a negative, discouraging impact on appropriation of SMTs for self-management.
of chronic illness. (Refer to Section 9.3 for a detailed explanation about factors which positively or negatively influenced appropriation in this study).

**Extending MTA with enabling or disruptive affordances:** The fundamental MTA model does not account for enabling or disruptive effects of technology features on the accomplishment of a user’s tasks. Accordingly, this study extends MTA by drawing on affordance theory to account for the potential illness management outcomes that are enabled or disrupted by SMT technology features. The enabling affordances found in the present study which agree with previous work include narration/storytelling, identity, triggered attendance/considered participation, sensemaking and metavoicing (Majchrzak et al. 2013; Merolli et al. 2015; Treem and Leonardi 2012). Two unique affordances in the present study include creative outlet and compartmentalization. Disruptors to chronic illness management found in this study include emotional overload/metavoicing and misinformation. (Refer to Section 9.4 for a comprehensive discussion of affordances which enable or disrupt chronic illness management as found in this study).

Overall, this present study confirms the fundamental premise of the practice lens and highlights key differences which emerge in the social media context. In addition to the confirmation of the practice lens, this present study also extends MTA to the social media context to provide a holistic picture of social media appropriation in the context of chronic illness management. By applying a multi-theoretical practice lens, this present study was able to obtain rich and comprehensive insights on:

1) The unique process of appropriation of social media by chronically ill adults; opens the black box of appropriation in this context and identifies activities involved in the process of appropriation of SMTs for chronic illness management.

2) The personal, SMT community and technological factors that support or discourage appropriation of SMTs to better understand and manage fibromyalgia illness.

3) SMT technology affordances that enable or deter positive illness management practices and outcomes for adults with chronic illness.

**9.1.2 Towards an Integrated model for social media appropriation by chronically ill adults**

The next section outlines key findings from the present study to define an integrated model for social media appropriation by chronically ill adults. This model is an extension of MTA to the social media context augmented by SST and the theory of affordances to provide a complete
picture of social media appropriation by chronically ill individuals to better understand and manage their illness. Accordingly, the components of this model are presented based on the research sub-questions to address each class of findings. Further, a set of propositions are presented in each subsection to further theoretical development and summarize new insights obtained from the study.

9.2 UNPACKING THE PROCESSES OF SMT APPROPRIATION IN THE CHRONIC ILLNESS SELF-MANAGEMENT CONTEXT

In this Section, we address the first research sub-question:

*What are the processes undertaken by chronically ill adults to appropriate social media as part of their illness management practices?*

Our findings show that participants had different usage patterns for typical social networking or hedonically motivated appropriation of SMTs than the usage patterns displayed for carrying out illness management activities. First, adoption for some of the examined SMTs was due to their primary objectives: to connect with friends, family and others around shared topics of interest. For instance, informants on Facebook, YouTube and Instagram studies reported that they had adopted these SMTs initially for hedonic or social networking purposes. However, it was apparent that illness management needs served to trigger a distinctive set of appropriation activities. The findings of the present study go further to expose unique appropriation processes for single SMTs or across multiple SMTs for illness management purposes which are discussed below:

**9.2.1 Single SMT appropriation activities**

Findings in the present study demonstrate that the examined SMTs were appropriated in a multipurpose manner to conduct different activities through the same technology tool. This raises the question: *why did study informants appropriate SMTs in a multipurpose manner?* A potential explanation for this could be attributed to the stigma associated with chronic illness, because of stigma there was a need for privacy which triggered study informants to try to compartmentalize their illness management needs from the other social networking activities they carried out on the examined SMTs. In this study, findings highlight the idea that a need to privately conduct illness management practices served as a key driver for this divergent appropriation practice. Accordingly, this new insight leads to the following proposition:
Proposition 1: Both the stigma associated with chronic illness and emotional/psychological illness management needs such as privacy strongly influence the way in which SMTs are appropriated by chronically ill adults.

An important finding from this study was that these individuals distinguished their appropriation for illness management purposes from their other interactions with these SMTs. This was evident because in three cases (Instagram, YouTube and Facebook), study informants already had existing accounts and made use of these SMTs for standard social networking activities before the shift to illness management appropriation practices. This finding corresponds with some prior studies which stated that people actively select how they apply technology features and this accounts for differences in how appropriation occurs (DeSanctis and Poole 1994; Markus and Silver 2008). In keeping with the task-technology-fit class of studies (Gattiker and Goodhue 2005; Goodhue et al. 1995), it was apparent that study informants chose SMTs based on their chronic illness needs at a given point in time (Refer to Chapter 8, Section 8.1 for a needs based assessment of each SMT). Yet, in contrast with the basic utilitarian premise of task technology fit studies, it was evident that appropriation of SMTs for chronic illness management in this study was also influenced by emotional/psychological illness management needs. Furthermore, in the Reddit case, the need to carry out illness management practice and access resources anonymously from others with fibromyalgia was found to trigger the adoption of the SMT in the Reddit case study. Taking this idea further, it was clear that each of the four examined SMTs supported appropriation for illness management to differing degrees for example:

- Facebook allowed the same profile traverse various spaces and interact in differing areas of interest as the same persona/profile. Facebook SMT allows the formation of groups and pages around topics of interest such as fibromyalgia. Key informants were able to use their main profile to interact on fibromyalgia groups and pages to conduct illness management specific activities.

- YouTube allowed the user to engage in various activities by either creating multiple channels to cover various interests the YouTuber has. The YouTube website also allowed users to view videos by others in the community.

- Reddit allowed the user to navigate a diverse set of virtual rooms in order to accomplish various tasks through the SMT. On the Reddit case, this was evident to the extent that the user profile may have a different signature on each subreddit,
and a user could also make use of throwaway accounts to during appropriation of Reddit. and;

- Instagram had the highest inbuilt support for this versatility through the multi-profile function that allowed users to compartmentalize their various areas of interest which are treated as discrete environments separate from their default SMT account.

Consequently, this study clearly shows that adoption was influenced not only by the need for illness management resources or social support but also by the need for privacy, to compartmentalize illness management practices and manage illness stigma or fear of alienating friends/family. In the cases of Facebook and Instagram, an account is required before most content can be viewed or consumed. Further, study informants reported that they did not post about fibromyalgia on their profiles. Similarly, informants from the Reddit case study displayed a similar aversion to the idea that friends and family members being exposed to their illness management activities. (Refer to Figure 9.1, below).

While informants indicated that they had accounts on other social media tools, they had appropriated Reddit because of the anonymity inherent in its design through the depersonalized profiles and usernames. Conversely, informants from the YouTube case did not display similar reticence towards being open about their illness management practices or struggles with fibromyalgia. Instead, they created accounts and pages openly across numerous SMTs to act as advocates and work towards eliminating the shame and stigma surrounding the experience of chronic illness. A potential explanation for this difference in how the influence of privacy differed in the case studies could lie in the idea that YouTubers had already made a conscious decision to be public about their struggles with fibromyalgia. Their motivation to advocate and bring visibility to the “trash-can disease” far outweighs privacy concerns.

Moreover, another factor that could explain this lies in monetary benefits that motivate the adoption of YouTube. Study informants also discussed the frequency of their interaction with these SMTs for illness management purposes and indicated that they visited these sites daily even if they did not further interact with members of the community.
Figure 9.1 Social media appropriation model for chronic illness management
When asked to explain reasons for daily interaction with the examined SMTs, study informants shared that they indicated that they interacted with the SMTs multiple times a day to stay informed about events and discussions in their communities. This study at hand illustrates different phases in the appropriation process applied by chronically ill users to access resources needed to carry out illness management tasks.

In this study, the examined SMTs are applied by chronically ill users to perform illness management tasks related to accessing resources such as information and emotional support needed to manage the daily challenge of fibromyalgia. This set of findings diverge from the propositions of some recent studies which had suggested a notion of inseparability in the process of social media appropriation either as “imbrications” (Treem and Leonardi 2012) or “entanglements” (Orlikowski 2009; Scott and Orlikowski 2014). Instead, our study identifies distinct processes that are carried out by chronically ill users when applying an SMT to illness management related tasks. The single SMT appropriation patterns in this study are broadly demarcated as i) tentative appropriation pattern; ii) reactive appropriation pattern; iii) proactive appropriation pattern and; iv) adaptive appropriation pattern of a single SMT for chronic illness management. Accordingly, the next sections (1-5) leads the following proposition:

**Proposition 2**: Chronically ill adults may persist in an appropriation pattern (static) or may switch between different appropriation patterns (dynamic) on a given SMT based on their evolving illness management needs.

1. **Tentative appropriation pattern**

A tentative appropriation pattern denotes activities where the user can view and interact with the SMT but retains a level of disengagement or disentanglement from the community through lurking to learn about their illness. Through the tentative pattern, SMT users can retain a high level of privacy and are hidden from others in the community, but they retain access to content posted by other members.

Our study informants shared that when they had initially joined/adopted the examined SMTs for illness management, they practised tentative appropriation pattern by lurking on these SMTs where possible. In this study, it was evident that tentative appropriation gave users a sense of belonging to the community while also granting access to resources that allowed them to learn how to better manage their illness. In the examined cases based on explicit community formation, it was apparent that a vast majority of members were lurkers who
silently derived illness management resources without the need to further engage with others in the same community. This finding agrees with some previous studies which suggest that lurking allows users to obtain information and emotional benefits of membership to the chronic illness community at little personal emotional cost (Chung 2014).

In addition, the present study develops this idea to highlight another function of tentative appropriation—it allowed newer members of the community to observe and learn the norms and rules before interacting with others. Findings in this study show that for some users the tentative pattern/lurking may not be the final step in the appropriation process but could be a step that users return to depending on their ability to continually interact with others in the community. All four examined SMTs allowed tentative appropriation patterns for example:

- Reddit users could lurk on or search through the fibromyalgia subreddit to view posts and comments made by other users on Reddit SMT. Tentative pattern allowed them to stay informed on the topics under discussion in the community, giving access to informative and emotional resources on Reddit SMT. Reddit users could also subscribe to specific subreddits such as r/fibromyalgia to remain aware of any new posts that were created by other more active community members.

- YouTube users could search through and view videos uploaded by YouTubers without logging into the service and so they could retain access to informative content about fibromyalgia or could feel like a part of the community without pressure to interact in the comment section. In the YouTube case, all informants had stated that they began their journey to becoming YouTubers through viewing videos and subscription to channels about fibromyalgia.

- Tentative appropriation pattern allowed Instagram users to search for or follow a term to access posts and profiles that discussed fibromyalgia illness which are marked with illness specific hashtags such as #fibromyalgia. Consequently, they could access information or validation through the posts and memes uploaded by others in the ad-hoc fibromyalgia community on Instagram. and;

- Facebook users practised tentative appropriation pattern by joining a group or following a page. Tentative appropriation allowed them to access posts or other content uploaded in those spaces either by directly going to the space or by getting the latest content in their newsfeed or notification features. Users could also mark
a specific post to be notified about any new content on it, thereby remaining a silent part of the online conversation.

2. Reactive appropriation pattern

A reactive appropriation pattern refers to activities where the user engages in response to actions by others in the community. Regarding reactive appropriation pattern, informants also described activities such as the process of liking and reacting to content posted on these SMTs, explaining that it allowed them to show support or disapproval to content while also giving them a façade of privacy. Liking and reacting allowed members to acknowledge posts or comments and offer emotional support to other users in the same community. In this study, informants also shared that they practised reactive appropriation to draw more attention to a post or comment made by another member in the community. For example, in the Reddit case, key informants explained that if they did not know how to help a poster but felt the user deserved a response, they upvoted or liked the posted content to help draw others attention to it. Previous studies have overlooked this intermediate process to assert a strict dichotomy of interaction patterns on SMTs (lurking versus posting) because they had been based on older technology types such as discussion boards with limited functionality (Chung 2014). Therefore, this finding extends technology appropriation and social media studies to include an intermediate phase between tentative lurking activities and proactive posting activities on SMT. In doing so, our findings shed light on how reactive appropriation supports appropriation of select technology features by users to achieve their desired objectives. Key informants on three cases shared that this was their primary mode of interaction with others and they hoped to express solidarity and support through reactive appropriation patterns. Some study informants shared that being on the receiving end of reactive appropriation pattern left them with mixed feelings. While study informants appreciated that someone had read/ interacted with their content, they found this low level of engagement frustrating as it did not directly address their posted concerns. Our study showed that reactive appropriation patterns were the most commonly occurring interactions on all the examined SMTs.

- Study informants on Reddit could upvote and downvote posts or comments which had a direct impact on the ranking or visibility of a post. According to these informants, they aimed to bring greater visibility to the post and direct the attention of more experienced Reddit users who could help the poster. Also, upvoting or downvoting was used by informants to indicate their level of
agreement with the shared content, while avoiding direct discussion with the poster.

• In the YouTube study, logged in users could like, favourite and dislike videos posted by other chronically ill YouTubers on YouTube website. These reactive interactions do not directly impact the ranking of a video in the search results on the site. Still, they are useful to the YouTuber who created that video content because it serves to inform YouTubers on the engagement and audience reaction to their uploaded video content. Our study informants did not discuss their reactive appropriation practices but indicated that they found reactive appropriation from their audience to be a useful metric for deciding on what type of content their channel would produce.

• The Instagram SMT only allowed users to like content, but similar to the other studies; reactive appropriation was the most common interaction observed by the researcher. Also, study informants suggested that liking allowed them to engage with others and show support.

• Facebook SMT supported a wide range of reactive appropriation actions because it had a large number of emoticons such as liking, loving, anger, sadness and anger. Consequently, this suggests that reactive appropriation on Facebook allows study informants to engage in exchanges of emotional support. For instance, study informants can use the sadness emoticon to show empathy with others in the same who post about a distressing event.

iv. Proactive appropriation pattern

A proactive appropriation pattern refers to those activities where the user is at the forefront of activities within the SMT. The more proactive appropriation dimension of posting and commenting served to generate and maintain conversations in these communities. This finding supports the idea that proactive appropriation allows users to receive additional benefits such as social interaction and emotional disclosure (Chung 2014; Han et al. 2014). Further, the present study asserts that proactive appropriation facilitates the exchange of information support, emotional support and solicitation of material support. In this study, proactive appropriation patterns were carried out by users to seek help, to vent about challenges and to offer encouragement to others in the community. For instance, the range of proactive appropriation patterns in the present study included creating weekly accomplishment posts,
where other users could comment about positive things that had happened to them that week, as seen in the Reddit and Facebook cases.

However, in contrast with the findings from previous studies by Han (2014) or Chung (2014) findings in this study demonstrate that proactive appropriation pattern could result in adverse emotional outcomes (Chung 2014; Han et al. 2014). The present study showed that community-based SMTs such as Facebook and Reddit contained many depressive posts about suicide or venting about illness symptoms which was perceived as sources of emotional overload by study informants. Proactive appropriation patterns on Instagram involved creating memes to share personal experiences with the aim of spreading awareness to gain support for people living with fibromyalgia. While YouTubers proactively appropriated the website as a means of exchanging emotional, information and monetary benefits.

v. Adaptive appropriation pattern

In this study, adaptive appropriation patterns denote the workarounds applied by users to appropriate an SMT for illness management. Regarding adaptive appropriation pattern, we make the following proposition:

**Proposition 3:** Chronically ill adults engage in adaptive appropriation to mitigate challenges such as lack of ease of use and restrictive technology policies to bring useful SMTs into their chronic illness self-management practice.

As indicated in Figure 9.1, restrictive technology policies or perceptions that an SMT lacks ease of use serves to encourage adaptive appropriation pattern in an effort to mitigate the perceived limitations of the SMT. For example, it was clear that while study informants noted the inherent value and usefulness of YouTube, they considered its feature-set insufficient for their YouTubing tasks. Therefore, informants from the YouTube study had to conduct multiple workarounds which included applying: 1) external technologies to create useful video clips (cameras, film production setup); 2) editing tools (software packages) to enhance the presentation of this content and; 3) integration of other SMTs to allow them to message others in their community. Other augmentations these cohorts carried out involved using browser or mobile based applications to enhance the functionality of these tools as was mentioned in the Reddit case. Our finding support some previous studies which suggest that users may include other technological artefacts to adapt a technology (in this study, SMTs) to their task if they find the technology under appropriation to be useful (Mendoza et al. 2010; Orlikowski 2000).
Furthermore, our study extends this idea to clearly show how chronically ill users modify an SMT technology in illness management practice by utilizing other technologies to extend the capabilities of the studied SMTs. It was apparent that in addition to usefulness, lack of ease of use also served to trigger adaptive appropriation in the present study. Similar workarounds were not discussed by informants in the Instagram or Facebook case studies possibly because they are cleanly designed but have a comprehensive set of features. Therefore, they were perceived as easy to use.

Taken together, this set of findings unpack the appropriation processes involved in utilizing SMTs as part of illness management for fibromyalgia. Our study also goes further to suggest that tentative, reactive and proactive appropriation are not inflexible/static stages for chronically ill adults. Rather, our study suggests that some users alternate between these patterns based on the continually evolving influences exerted by the SMT environment such as changes in features or community structure. This class of findings extend this idea to suggest another cause for this alternating appropriation phases lies in the inherent challenges of life with fibromyalgia—the illness may exert physical or emotional effects which directly impacts how study informants can engage with SMTs based on their daily health needs. Moreover, this study argues that the aforementioned appropriation patterns may occur during the process of appropriation of a single SMT or parallel appropriation of more than one SMT as indicated in Figure 9.1 above.

9.2.2 Parallel appropriation of multiple SMTs

Parallel appropriation denotes appropriation of multiple SMTs as part of a toolkit based on the capabilities of the selected SMTs such as Instagram for creating awareness or advocacy and Facebook to discuss with others about coping with fibromyalgia symptoms. One of the more significant findings from the present study is that these informants appropriated multiple SMTs and other technologies for illness management which were appropriated to create an online illness management toolkit. Overall, this study presents strong insights to inform theory on appropriation process for multiple SMTs. This finding is unique and explains the effects that arise from having access to a plethora of SMTs with different capabilities. This raises a fundamental question—what factors motivate parallel appropriation of SMTs? This study outlines several issues that drive parallel appropriation of different SMTs to carry out different aspects of illness management based on their daily needs (Refer to Chapter 8, Table 8.1). This finding contrasts with previously conducted work on SMT use in an organizational setting.
because individuals in the general public are not restricted to one pre-selected SMT to apply for their task. Accordingly, this set of findings prompt the following proposition:

**Proposition 4:** Parallel appropriation of multiple SMTs enable chronically ill adults to develop a toolkit to better support more comprehensive illness management practices based on the different features and capabilities offered by multiple SMTs.

First, the majority of these key informants reported having multiple SMT accounts across a range of technologies including Tumblr.com, Pinterest.com, YouNow.com and numerous others in addition to the SMT account they had for the case study. This finding provides empirical backing for some previous studies which had suggested that modern IT artefacts support multi-communicating through a variety of different technologies (Fulk and Gould 2009). Our findings take this idea further to show how the proliferation, availability and cost of SMTs influence appropriation behaviour in the study context. For example, the study informants viewed SMTs as parts of their illness management toolkit, and the adopted SMTs all served different functions for their users.

Through the vast ecology of free to use SMTs, the user could switch spaces and identities virtually depending on their illness management-related needs at any point in time. For instance, some study informants made use of Tumblr or YouTube for illness advocacy or to exchange emotional support while their information support needs were mostly satisfied by community-based SMTs such as Reddit and Facebook. Another potential reason for the parallel appropriation process could lie in privacy mechanisms and shame. A chronically ill adult who is uncomfortable with interacting in a community-based SMT like Facebook due to shame, fear of disagreements or a desire to remain anonymous could appropriate an SMT like Reddit, create a throwaway account and ask questions (Refer to Chapter 4).

Moreover, parallel appropriation in the YouTube study was applied by YouTubers so they could increase the visibility of their channel, to gain more viewers through other SMTs like Instagram and Twitter. Informants in the YouTube study complained about the restrictions enforced by the technology policy which by default excluded channels focused on niche concerns like fibromyalgia from benefitting from monetization. Therefore, they included websites like Patreon.com to access donations from subscribers. Some study informants also disclosed that they had accounts on illness-specific sites such as mdjunction.com but interacted with those less because they were not as active or complete as the other SMTs which
allow them to appropriate for numerous tasks, not just illness management. Specific examples from each case study include:

- **Reddit parallel appropriation**: study informants on the Reddit case disclosed that they also used health specific social media sites like healthunlocked.com for illness management. Some indicated that they had Facebook accounts but did not feel comfortable having fibromyalgia related content associated with them on the Facebook SMT because of fears that friends or family would see their posts.

- **YouTube parallel appropriation**: YouTubers adopted other SMTs like Facebook, Twitter and Instagram to drive up views for their uploaded video content. Parallel appropriation also enabled interaction with subscribers who were too shy to comment on their video uploads on YouTube.

- **Instagram parallel appropriation**: Instagram study informants disclosed that they all had Facebook accounts. Some informants were members of Fibromyalgia groups on Facebook but were reluctant to interact on those spaces. When queried about this they disclosed the feeling of shame about having fibromyalgia at such a young age and fears of not being believed by others in the Facebook group who were older. Two informants who were sisters created Facebook groups specifically for younger individuals with chronic illness.

- **Facebook parallel appropriation**: Most Facebook study informants shared that they also had other SMT accounts for illness management purposes which includes SMTs like healthunlocked.com, mdjunction.com, webmd.com and myfibroteam.com. These SMTs were used in parallel to exchange information and emotional support. One informant in that study indicated that due to time constraints, they were unable to have any additional SMTs than Facebook (the informant was an administrator-Facebook04).

### 9.3 A FRAMEWORK OF INFLUENCES ON SMT APPROPRIATION FOR CHRONIC ILLNESS MANAGEMENT

This section addresses the second research sub-question:

*What factors influence appropriation of social media tools by chronically ill adults?*

Findings in the present study suggest that influences on appropriation of SMTs by chronically ill adults are multidimensional and related to 1) personal factors that trigger or encourage appropriation of SMTs as part of chronic illness management; 2) SMT community
factors that support or discourage appropriation for illness management and; 3) SMT technology factors that support or discourage appropriation for chronic illness management. Subsequent sections discuss supporting or discouraging influences on appropriation in this present study.

9.3.1 Influences that support appropriation of SMTs for chronic illness management

This study highlights the challenges inherent in living with chronic illness such as Fibromyalgia. Some of the challenges reported by these key informants include reduced mobility, depression, and sleep disorders like insomnia which disrupted their quality of life daily. Accordingly, there were several personal factors that encouraged appropriation of SMTs in this study which are discussed below.

1. Personal factors that support appropriation of SMTs

In this study, we unpack the challenges of invisible illness; unlike some chronic diseases like diabetes which have clear cut diagnostic criteria, study informants stated that diagnosis for them was a process of elimination, fibromyalgia was considered an invisible illness. Study informants expressed frustration with this aspect, terming the diagnosis as a “trash can” term used as a catch-all for individuals who display several similar symptoms like chronic pain, fatigue and depression. Our findings suggest that adoption of these SMTs is triggered by illness-related needs that drove appropriation for illness management purposes. Because there are no clear-cut diagnostic criteria or treatment plans for coping with this debilitating illness these individuals adopted SMTs as part of their chronic illness management efforts in hopes of gaining access to a community of similar others. Further, this study suggests dimensions of personal factors that support and encourage appropriation of SMTs by chronically ill adults relating to task, emotions and financial factors (See Figure 9.2).

This class of findings align with and extends previous studies which suggest that SST concepts like information and emotional support exchanges motivate chronically ill individuals to participate on social media technologies (Pousti et al. 2014; Wang et al. 2017). The next sections discuss unique findings on three classes of supporting factors that were found to influence appropriation of SMTs in this study relating to: i) task-related factors, ii) emotional/psychological factors and; iii) financial factors.
Figure 9.2 A framework of supporting and discouraging influences on social media appropriation for chronic illness
i. Task-related factors that support appropriation of SMTs: It was clear that these individuals have unique challenges of fibromyalgia because there is no established treatment plan that worked for all sufferers. Rather, these cohorts had to learn through experimentation to discover which coping practices or medications worked best for them to manage their illness. This notion was reinforced by the study informants who shared that there is a lack of specific medical tests to support a fibromyalgia diagnosis. Therefore, this set of findings lead to the following proposition:

**Proposition 5:** Chronically ill adults appropriate SMTs to become more knowledgeable about their illness and overcome disparity of care which enhances their self-management practices, leading to improved health outcomes.

Through appropriation of an SMT, chronically ill adults gain access to others treatment plans, crucial behavioural changes such as dietary restrictions to avoid triggering flares and coping information such as the use of weighted blankets or exercise therapy. The present study shows that information support exchange was essential to these vulnerable cohorts because it served to provide them with coping practices from others which was applied to aid in the daily management of fibromyalgia conditions. Accordingly, this finding agrees with previous studies on the value of information support exchanges to cope with chronic illness (Beck et al. 2016; Wang et al. 2017).

This prompts the question: *What were the implications of information support exchanges on SMTs for chronically ill adults?* Our findings establish that SMT interactions aid chronically ill adults to become more knowledgeable about fibromyalgia. Most informants considered themselves more knowledgeable than their doctors about fibromyalgia owing to their own experiences with the illness in combination with the learning that occurred on these social media sites. Further, our study shows that these challenges were exacerbated further for cohorts who live in countries like Spain or Japan who relied heavily on peers in SMTs because fibromyalgia is not well understood in their countries of residence. Our study also shows that information support received through the adoption of SMTs had valuable impacts on the medical care of informants in countries that had less understanding of fibromyalgia illness in terms of diagnosis, medications and coping strategies. Thus, this study provides evidence which supports the notion that SMTs could serve as viable
tools to address disparities in access to adequate healthcare among individuals from different geographic and socio-economic backgrounds (Agarwal et al. 2010; Goh et al. 2016).

Our findings demonstrate key differences in how information support exchanges occurred based on self-efficacy: more experienced cohorts were information-givers, tending to respond to queries on illness management, coping strategies and other related issues. From their perspective, they were willing to share their accumulated knowledge from years of dealing with fibromyalgia and navigating the medical service terrain to obtain better health outcomes for themselves. Further, more experienced individuals also educated their peers on how to advocate for themselves and explain their limitations to friends and family. Their information giving activities also extended to financial and legislative issues such as insurance options or obtaining disability pension benefits. Our findings suggest that for those with more experience or good medical support, information shared in the SMT community by others helped them stay abreast of the latest developments in the medical field concerning better management and treatment of fibromyalgia.

Conversely, newly diagnosed members took on a more information-taking role, to learn the necessary coping strategies, terminology and other details needed to develop effective illness management practices. Therefore, they needed to learn about how to manage their illness from others who knew and had a first-hand understanding of their lived experiences with fibromyalgia. Further, this set of findings support some previous studies which suggest that perceived levels of self-efficacy in terms of experience with a chronic illness affects information support exchanges in the SMT environment (Bernardi and Wu 2017; Bodenheimer 2002; Cohen and McKay 1984).

Additionally, this study found that information exchanges on SMTs are important because they provide participants with evidence which are applied to their relationships with their GPs, empowering them to advocate for themselves in their care and with others who may not understand their illness. Therefore, this present study found that self-advocacy and empowerment were facilitated by these information support exchanges via these SMTs in general, encouraging participants to become expert patients. This finding aligns with some previous studies which discussed social media adoption as a source of patient empowerment (Deng et al. 2013; Fan et al. 2014; Fernández-Luque and Bau 2015; Greenhalgh 2009). Taking this idea further, findings
also indicate that informants are also motivated to engage in activism on SMTs to promote understanding and visibility for fibromyalgia by the general public. Thus, self-advocacy and activism were influential factors on appropriation of SMTs in this study.

Therefore, gaining access to others’ treatment plans, learning more about fibromyalgia, gaining access to tested coping strategies served to support appropriation of SMTs in this study.

ii. Emotional/psychological aspects of illness management: Our study also suggests that the emotional toll of fibromyalgia served to trigger appropriation of SMTs. To further unpack the emotional aspects of chronic illness, we put forward the following proposition:

Proposition 6: Appropriation of SMTs by chronically ill adults reduces the emotional/psychological repercussions such as shame that arise from the stigma of having a chronic illness.

Because of a lack of specific tests to diagnose fibromyalgia, most informants had suffered from their illness for years before obtaining a diagnosis that then allowed access to better treatment options. Consequently, obtaining a label through diagnosis was a relief as they were able to better evaluate how to live with fibromyalgia, and felt validated by their diagnosis. Still, our study suggests that chronically ill adults deal with the stigma of having an ‘invisible illness’. Despite getting diagnosed, these individuals still felt ashamed of their condition because they did not want to appear to “complain too much” to their GPs, friends and family. Therefore, appropriation of these SMTs offered an opportunity to access a community of similar others where fibromyalgia could be discussed freely, without shame or restriction. Accordingly, our study agrees with some previous studies that highlight the role of stigma in chronic illness as a potential influence on the adoption of SMTs by chronically ill adults (Beck et al. 2016; Wang et al. 2017).

However, this study goes further to suggest that stigma triggers a distinct set of appropriation activities for chronically ill adults. Our findings demonstrate that shame triggers a distinct set of appropriation activities that are considered separate from typical SMT use by the study informants. For instance, the present study showed that informants in three cases (Reddit, Instagram and Facebook) created separate spaces to
connect with and discuss fibromyalgia with other chronically ill adults. In the Facebook study, key informants did not discuss fibromyalgia on their profile pages, rather they joined fibromyalgia specific groups to carry out illness management activities. In the Instagram study, most study informants compartmentalized their illness management practice from their typical social networking practices by creating illness specific profiles that were not associated publicly with their default profiles.

Another key finding in this study at hand concerns isolation due to chronic illness (Refer to Figure 9.2). In this study, key informants appropriate SMTs to combat the loneliness and isolation they experienced because of fibromyalgia. For these individuals, SMTs are an opportunity to combat the isolation that comes with a physically and mentally debilitating chronic illness by connecting with empathetic others. Thus, this study agrees with the idea that social support may act as a buffer against stressful life events (Cohen and Wills 1985; Huh et al. 2016; Lazarus 1993). Further, this present study takes this idea further to argue that SMTs provide an opportunity to combat the isolation of a poorly understood chronic illness. Accordingly, these sets of findings suggest that appropriation of SMTs is supported by emotional factors that aid chronically ill adults with combatting the stigma, shame, isolation, loneliness and compartmentalize their illness from other areas of their daily lives.

Our study suggests that SMTs provide a safe space for emotional exchanges which allow chronically ill adults feel validated, accepted and seemed to shield them from the stigma they experience when dealing with others in the real world who did not believe or understand the impacts of fibromyalgia. This idea was remarkably clear among study informants with less access to offline supportive systems, especially in the Facebook and YouTube studies. For instance: Facebook04 was an unemployed widower with two adult autistic children/dependents who had little access to help apart from the monthly government disability pension he received. Similarly, those with offline supportive systems equally found emotional support through participation on these tools because they experienced feelings of guilt due to their constant health struggles and did not want to allow fibromyalgia to pervade all facets of their lives. These individuals primarily used these groups as an additional source of emotional support to maintain their sense of well-being and prevent them from damaging their relationships with family and friends.
Another significant finding in this study suggests that social support acted as a motivation for appropriation of SMTs by chronically ill adults. This finding aligns with previous studies which suggest that social support exchanges influence the adoption of SMTs by chronically ill adults (Goh et al. 2016; Wang et al. 2017). Yet, findings differ from SST class of studies because findings suggest that social support functions as a sub-component of emotional support rather than a distinct from it.

Certainly, for these vulnerable, isolated individuals there is an emotional need for companionship and understanding that is being satisfied through the social support concept. Further, this study’s findings show that social support relationships were forged to perform different degrees of relational intimacy. Study informants had friendships that ranged from “on-site-only” friendships to romantic relationships, thereby facilitating social support for these individuals. In the Facebook study, informants demonstrated a marked willingness to befriend peers they meet on these social media tools, actively interacted with others, exchanging contact details, becoming pen pals, displayed a willingness to meet offline and in one instance becoming romantic partners.

In contrast, informants on Reddit seemed to have an ambivalent attitude towards social support—some informants indicated that they were satisfied with interacting either through their profiles on the site, while a few were willing to exchange other social media details and interact there. None had any intentions to meet in “real life” as a result of a combination of concerns: trust, privacy, restrictions due to physical and temporal limitations. For instance, some informants were uncomfortable with breaking through the barrier/distance created through the profiles while some other informants indicated that they did not have energy or time for socializing in their real lives and so considered an extension of the friendships forged on these SMTs to be unnecessary distractions. Rather, they preferred these relationships as online-only interactions which they could opt into or out of without it affecting other aspects of their lives.

Taken together, this set of findings suggest that the desire for emotional support is a powerful motivation for appropriation of SMTs by adults with fibromyalgia. Through emotional support, they could build different types of relationships such as friendships or romantic relationships. This class of emotional factors supported appropriation to help study informants cope with the isolation, loneliness, loss of identity and stigma they experienced because of their fibromyalgia diagnosis.
iii. Financial factors that support appropriation of SMTs: Another important finding from this present study pertains to the influence of financial support on appropriation of SMTs by some chronically ill adults. First, this set of findings prompt the following proposition:

**Proposition 7:** Chronically ill adults are able to obtain increased knowledge of and access to financial aid to support their illness journey, such as useful information on obtaining disability schemes through appropriation of SMTs.

Due to the physical toll of fibromyalgia, it seemed that these individuals were also motivated by the pursuit of financial/monetary benefits from appropriation. In contrast to other studies which had not reported on the supporting influence of financial factors, our findings suggest that it is a powerful influence for appropriation of some SMTs. Therefore the present study’s findings align with the basic premise of SST which states that social support may also involve the exchange of financial/material resources (Lakey and Cohen 2000; Shumaker et al. 1984). Recently, studies which have applied SST to investigate motivations for appropriation of SMTs for chronic illness management have not accounted for the financial/material aspect which suggests that in an online/SMT setting the exchange of financial/material resources does not impact appropriation (Hajli et al. 2014; Pousti et al. 2014; Wang et al. 2017). Conversely, this study contends that opportunities to exchange financial/material resources served to motivate appropriation to varying degrees across three of the cases: YouTube, Instagram and Facebook. Our findings reveal that most key informants were unable to hold jobs because of the physical and mental impact of fibromyalgia therefore, SMTs offered an alternative means to gain financial support. In the Facebook study, informants regularly discussed how to file disability claims and obtain government pensions to assist with the costs of daily life.

This study also argues for other mechanisms within the financial support concept such as monetization and building a brand. Our findings show that YouTubers were especially motivated by financial factors, they made use of YouTube’s analytics/monetization features to gain monetary benefits to sustain themselves. Similarly, a few key informants from the Instagram case created items related to fibromyalgia-like t-shirts and mugs which were sold to followers to obtain financial benefits (see Chapter 4, Section 4.3.1). Monetary influences were not observed among the informants on Facebook or Reddit. Although one Facebook informant reported that
she had written a book and formed a group based on her book to help others, she did not actively promote this book on the groups where she was a member. Instead, she seemed to keep group administration activities separate from the promotional activities carried out for the fibromyalgia book.

Accordingly, this set of findings asserts that financial factors support the appropriation of SMTs by chronically ill adults because of the restrictions imposed by their illness. Fibromyalgia affects the ability of individuals to maintain jobs because of its physical and mental impacts on sufferers. Therefore, we found that individuals are motivated to appropriate some SMTs to improve their chances of gaining disability pension, to gain monetization benefits and by the prospect of building a brand.

2. SMT community factors

An important finding in this work concerns the impact of SMT communities on appropriation. In this study, engagement with the SMT communities served as an important mechanism to support the illness management needs of chronically ill adults. To accomplish the personal supporting factors outlined in prior sections, it was necessary to be a part of an SMT community with other chronically ill adults. Further, our findings indicate that communities were forged in different ways based on the features of the SMTs; for instance, Reddit allowed explicit creation of subreddits for users who met specific criteria set by the site - these subreddits supported the formation of communities of profiles around a topic of interest. Similarly, Facebook allows the creation of groups and pages where users with similar interests could be added to these spaces either as members of the community (for Facebook groups) or as followers of the page (for Facebook pages).

Conversely, Instagram communities are formed in an ad-hoc manner through hashtags and around uploaded content which exposed similar profiles to interested parties (Bernardi 2016). YouTube communities are also formed in an ad-hoc manner around the channel created by the vlogger/YouTuber and community activities are carried out in the comments section under each video. In a sense, these accounts and profiles acted as avatars or personas where they could interact online without the physical limitations that arise from fibromyalgia. Because of these communities, chronically ill adults were able to overcome the limitations arising from a physically debilitating illness since they could interact effortlessly with others they meet online.
i. **Task-related supportive factors:** The SMTs included in the multiple case study allowed community creation, dissolution and roles based on individual performance within the community. This finding supports the notion of role appropriation reported by previous studies (DeSanctis and Poole 1994; Leonardi et al. 2016). To this effect our findings go further, showing that within these communities, users were able to negotiate roles for themselves, based on their health condition and disposition. These roles were a source of various activities within these groups as the more experienced members tended to act as a source of information, emotional support and encouragement for the newer members of the group. They also tended to be the attentive members of the group, policing and monitoring to ensure that the activities within the group complied with the policies of the group. Norms and rules were written in the sidebar and at a prominent location informing members of the acceptable standards of behaviour required for membership. This finding agrees with some previous studies which suggest that subjective norm and culture may influence appropriation outcomes (Davis 1989; Maier et al. 2015; Mendoza et al. 2010).

For the ad-hoc communities such as YouTube or Instagram, rules are set up by the owner of the content (YouTube channel or Instagram profile) but these are enforced by their followers/subscribers who regulate the activities of other users in the shared comment section, rising to the defence of the vlogger whenever any negative comments are submitted to the videos or images. Instead, informants from YouTube indicate that to some extent, their ability to control the types of activities that occurs in their comments section is due in part to the size of their channel- indicating that smaller communities are easier to regulate. To some extent, this idea is confirmed by the informants on Facebook who also indicated that enforcing norms and policies is easier when the community is smaller, and this is also a joint effort between the administrators/moderators of the community and members of that community.

Another significant finding in this work concerns the role SMT communities play to collectively make sense of fibromyalgia symptoms and management. This study found that SMT community members regularly discuss their medications or new symptoms to gain access to other’s experiences. Through these interactions, study informants were able to educate themselves on if a symptom they currently experienced was related to fibromyalgia and about the side effects of medications prescribed by their primary physicians. A positive side effect of collective sense
making was that SMT communities served to filter through dangerous or misleading information reported by their members which had a protective effect. This set of findings expand on the information support concept from previous SST studies to expose the role of information support within illness self-management and reveal mechanisms through which chronically ill adults’ benefit from information support in an SMT environment. Collective sensemaking also extended to discussions about getting diagnosed for new members in the community who had not yet obtained a diagnosis. For instance, in the YouTube study, information from another YouTuber led to a study informant’s diagnosis which also motivated her to proactively appropriate YouTube SMT. Thus, this set of findings clearly show the significant role an SMT community plays to aid the task related aspects of managing chronic illness.

ii. Emotional/Psychological supportive factors: This study reveals that fibromyalgia causes a sense of lost identity due to the bleak prognosis, given that fibromyalgia is thought to be progressive. Accordingly, the SMT communities serve as a mechanism to aid chronically ill members to obtain a more positive outlook, leading to a revised sense of identity. The present study takes this idea further because it demonstrates that revised illness identity was forged through different activities like creating shared terminology (“fibro-warrior”, “spoonies”, “spoon theory”), creating memes, developing identifying images such as the fibromyalgia butterfly and identifying with celebrities (Lady Gaga, Avril Lavigne, Morgan Freeman) who are thought to also have fibromyalgia. As a result, these interactions on SMTs encourage informants to develop a more positive outlook on their illness, resulting in them gaining a positive, revised sense of identity. This finding extends some previous studies that have discussed the positive effects an online community could exert on emotional states of chronically ill individuals (Wang et al. 2017).

Accordingly, this set of findings emphasize the crucial role of an SMT community for obtaining task and emotional resources to better understand and manage fibromyalgia illness.

3. SMT Technology factors

A unique finding from this thesis was that despite having access to health-specific SMTs, study informants shared that they preferred the environment provided by these general-purpose public SMTs. When asked why, study informants indicated that the convenience of these tools play a role because they can pursue multiple
activities through the same tool. Implicit in this value-assessment is the notion of the free-to-use, accessible nature of these SMTs which allows them to conduct multiple tasks as well as illness management activities through one online location/platform. These four examined SMTs are free to use and accessible to anyone with an internet-capable device such as a smartphone or a personal computer. This set of findings align with adoption and diffusion literature which had suggested that cost is a potential influence on adoption or use of a technology artefact in the public domain (Carroll et al. 2007; Venkatesh et al. 2012). Further, in the social media context, accessibility of an SMT also serve as an influence on adoption and continued use in this study at hand. Because these SMTs are publicly available, globally accessible and free, the barriers to adoption were negligible particularly in comparison to potential benefits for illness management. Accordingly, this set of findings lead to the next proposition:

**Proposition 8:** The characteristics and design of publicly available SMTs support the illness management activities of chronically ill adults because these technologies do not enforce strict usage contexts.

Each of the examined SMTs have different core capabilities, but due to the flexibility in the design of these tools, they are also able to support numerous types of activities/tasks in tandem. Taking this idea further, the examined SMTs did not enforce or explicitly prescribe a usage context to individuals, the features of the examined SMTs allow chronically ill adults to carry out illness management practices alongside hedonic social networking activities. Still, the features of these technologies shaped how they could be applied to illness management practices to different degrees based on qualities of the technology and its features such as familiarity, ease of use, purchase cost. For instance, in the Facebook case key informants were unable to state which features they applied to their illness management practices or which features they used the most. This study suggests that Facebook was easy to use or familiar to study informants, and so its features were not consciously noticeable to them. This “feature blindness” finding agrees with some previous research that suggested familiarity with technology could result in it “disappearing from view” as the users develop mental frames due to an inherited understanding of similar SMTs (Leonardi 2013; Mendoza et al. 2010; Orlikowski and Gash 1994).

In contrast, informants from the other three studies (Reddit, Instagram and YouTube) were conscious of the various technology features that made them more
challenging to use. For instance, informants in the YouTube study shared that YouTube was a complicated technology to use because of the elements involved in creating a video blog which included aspects such as editing or adding sound clips. Similarly, Reddit was simplistic in design, but users were dissatisfied with some of its functionality compared with other SMTs and so they augmented Reddit with browser plugins to provide the functionality they prefer. In contrast to some previous technology appropriation studies lack of ease of use did not appear to have a negative impact on appropriation in two case studies (Davis 1989; Hsu and Lin 2008). Rather, findings in the present study suggest that perceived usefulness was a more important supporting influence on appropriation of the examined SMTs for chronic illness management (Mendoza et al. 2010). Further, the present study unpacks perceived usefulness to contend that in the chronic illness context, perceptions of usefulness depends on the task the user aims to accomplish with the SMT. Rather, study informants described usefulness in terms of an SMT’s value to accomplish illness management tasks. This finding agrees with prior work that states the importance of perceived usefulness on appropriation outcomes (Davis 1989; Mendoza et al. 2010). Further, this study highlights the distinct differences that exist regarding factors that influence appropriation in a social media context compared to the traditional/organizational class of appropriation studies.

The present study reveals that SMT technology features were an important supporting factor on appropriation by chronically ill adults. The examined SMTs supported the development of communities in various forms: Reddit and Facebook support the explicit creation of groups through the subreddit feature or the groups/pages feature for each SMT respectively. Whereas Instagram and YouTube allow community formation in differing ways: Instagram allows users to find topics of interest through hash-tagging functionality, thereby allowing users to search by hashtags to find content related to their topic of interest. After that, users may follow profiles of interest, allowing ad-hoc community formation around content, more interestingly Instagram profiles exist separately from a user’s account, so this allows a level of anonymous communication with others and compartmentalization of illness management from other areas of interest for the user.

While YouTube allows direct communication from the YouTuber/vlogger, a global audience and communications/community are forged in the comments section
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of the video. Additionally, technology policies were not found to play significant roles in influencing the appropriation of SMTs by these chronically ill adults in three cases (Facebook, Instagram, Reddit). Instead for those informants, the policies that had the most impact on the appropriation and activities of these individuals were the policies that were informally developed by the community leaders. However, YouTube policies had a significant influence on how the informants from YouTube applied the tool to illness management practice. For instance, YouTube’s policies on media use, the media library and so on served to constrain the extent to which its users could create content without risking account deletion. Taken together, this set of findings suggest that ease of use, technology features, technology policies, familiarity and adaptability influenced the adoption and use of SMTs by chronically ill adults to varying degrees depending on the perceived usefulness of the SMT at hand.

The present study takes this notion further to suggest that the examined SMT offered varying levels of self-disclosure or self-presentation, but it seemed that a site with stronger anonymity mechanisms such as Reddit seemed to have a trade-off in the quality of connections reported by these users. This finding contrasts with some previous healthcare studies which had suggested that self-disclosure has a strong negative effect on the value of SMTs for self-management practices of chronically ill adults (Wang et al. 2017). Rather, findings in the study at hand indicate that the more anonymous or de-personalized the site, the higher the possibility for unwanted/undesirable behaviours like trolling, spamming and bullying which affects the atmosphere and level of emotional support derived through the appropriation of these tools. Although incidents of trolling were reported the most on Reddit, study informants on the other SMTS reported some encounter with trolling behaviour. For example, an informant from the Facebook case shared that she had left another fibromyalgia support group because she had been harassed by a male member who kept responding to her posts with aggression. Study informants on YouTube stated that while they had received trolling comments on their videos, it was not a problem because others in the YouTube chronic illness community such as commenters and subscribers protected them from trolls.

It is important to note that the features of all four SMTs continued to evolve throughout the study, exerting influence on how they could be applied to the illness management practices of chronically ill adults. In line with the evolving feature sets,
the policies and usage criteria for each of these tools were continually under revision particularly in terms of informally negotiated rules and norms formed by members of these communities.

9.3.2 Influences that discourage appropriation of SMTs for chronic illness management

The present study found two classes of factors that had a discouraging influence on appropriation of SMTs for chronic illness management.

1. Discouraging SMT Community factors

One of the more significant findings to emerge from this study points to the negative influence of spam on adoption and use of SMTs by chronically ill adults. Some key informants in the Facebook case (See Chapter 7) voiced concerns about spam and scams. For instance, some study informants in the Facebook case had disclosed their encounters with scammers who tried to spam and sell miracle cures to members of the community. This finding reinforces concerns expressed by some studies which have questioned the information credibility on online communities (Agarwal et al. 2010; Munson et al. 2013). The present study takes this idea further to demonstrate that this issue varies between SMTs. For instance, it appeared that the information quality on Facebook and Reddit was heavily scrutinized by other members of the group to protect against this issue of scamming. Another interesting finding, in the Facebook study, was the notion that despite the vigilance of members of the group, scammers often attempted to circumvent this scrutiny through engaging in private chats with others on the group.

Another discouraging factor in this study relates to trolling. Trolling involved the use of negative abusive language to attack some SMT community members and was observed in three studies, Reddit, YouTube and Facebook. Despite the vigilance of SMT community members and their intention to create a safe space for other chronically ill adults, it seemed that some study informants had experienced online bullying and in two studies, affected appropriation of SMTs. For instance, consequently, adoption or use of SMTs emotional support could result in emotional overload serving as a barrier to appropriation. This finding contributes to the growing body of literature that suggests that adoption of SMTs could also have negative psychological impacts on its users (Maier et al. 2015).
Further, when conflicts occurred in these communities, they often splinter, with some members separating from the larger group and creating their own space around an agreed topic of interest. This was only observed on Facebook and not similarly noted on any of the other cases.

2. **Discouraging SMT Technology factors**

Findings in the present study also highlight negative technology factors that could discourage appropriation which are observed in two studies: YouTube and Instagram. Study informants on YouTube reported the discouraging effects of the technology policies which resulted in the application of adaptive appropriation processes to overcome the restrictions of the monetization policy. Yet, the contentID policy still played a role to restrict appropriation but was not observed to deter appropriation of YouTube because as content creators, YouTubers understood and supported the SMT stance on copyright protections. This study also supports the discouraging effects of lack of ease of learning. For instance, YouTubers reported the complexity involved in creating and editing videos. However, lack of ease of learning was mitigated by the YouTube community who took it upon themselves to create step by step help videos. A possible reason for that could be due to the inherent perception of the value, usefulness and reach of YouTube SMT which mitigates the drawbacks of restrictive technology policies and lack of ease of learning. and Another discouraging factor on appropriation. This agrees with prior work which suggests that sometimes, supporting factors from technology use have a mitigating impact on the effects of discouraging factors.

9.4 **HOW DIFFERENT SMTS ENABLE OR DISRUPT SELF-MANAGEMENT OF CHRONIC ILLNESS**

This section addresses the third research sub-question:

> How do social media technology features enable or disrupt chronic illness management practices of chronically ill adults?

Accordingly, this section discusses the illness management possibilities offered to study informants by the examined SMT features and so these affordances are termed: enablers (affordances) and disruptors (constraints). Findings support current theory which suggests that social media allows users to act-through these SMTs and by-pass the limitations imposed on key informants due to their chronic illness or
geographical location. The next section discusses these enabling or disruptive affordances identified from this study and Table 9.1 provides a summary of these across all cases.

Table 9.1 Affordances which enable or disrupt appropriation for illness management purposes

<table>
<thead>
<tr>
<th>Affordances</th>
<th>Concept</th>
<th>Reddit</th>
<th>YouTube</th>
<th>Instagram</th>
<th>Facebook</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Enabler</strong></td>
<td>Belonging</td>
<td>High</td>
<td>High</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>Compartmentalization</td>
<td>High</td>
<td>Medium</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>Storytelling</td>
<td>High</td>
<td>High</td>
<td>Low</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>Sensemaking</td>
<td>High</td>
<td>Low</td>
<td>Medium</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>A creative outlet</td>
<td>Low</td>
<td>High</td>
<td>High</td>
<td>Medium</td>
</tr>
<tr>
<td></td>
<td>Considered Participation</td>
<td>High</td>
<td>High</td>
<td>Medium</td>
<td>High</td>
</tr>
<tr>
<td><strong>Disruptor</strong></td>
<td>Emotional overload</td>
<td>High</td>
<td>Low</td>
<td>Medium</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>Misinformation</td>
<td>Medium</td>
<td>High</td>
<td>High</td>
<td>Low</td>
</tr>
</tbody>
</table>

9.4.1 Enablers to appropriation for better chronic illness management outcomes

Findings from this present study clearly show that SMTs afford these informants with a sense of belonging to similar others in the community. There were eight distinct affordances identified that served to enable or disrupt illness management outcomes on each of the examined SMTs illustrated in Table 9.1, above. Based on the observed set of enabling affordances provided by SMT features (discussed next), the study makes the following proposition:

**Proposition 9:** Some SMT technology features (such as groups features, emoticons) empower chronically ill adults to achieve positive illness management outcomes by providing necessary affordances to address the specific emotional or task-related needs for daily illness management.

The first affordance concerns the sense of belonging these key informants derived through association with others having the same fibromyalgia condition. Because fibromyalgia is a debilitating chronic condition, study informants found it necessary to associate with similar others who could relate to their challenges through SMTs.

The **sense of belonging affordance** is in line with previous studies which had found similar affordances termed as: association (Treem and Leonardi 2012), connecting like-minded people to each other (Majchrzak and Markus 2012) or building a support network (Bernardi 2016) proposed by previous scholars (Kietzmann et al. 2011; Majchrzak et al. 2013). This affordance occurs because of the SMT capability to connect like-minded individuals to create and exchange content around illness
management. To enjoy a sense of belonging, study informants joined communities on the examined SMTs which were identifiable using similar descriptive terms such as fibro-warriors or spoonies. On community-based SMTs, these terms were explicitly disclosed in the name and description of the group or subreddit. Similarly, study informants in the Instagram and YouTube case had descriptive terms in their profiles to serve as calling cards for others with fibromyalgia.

The study at hand also proposes a compartmentalization affordance. Compartmentalization was viewed by these individuals as a means to conduct illness management activities separate from their other online activities. Compartmentalization was evident on these SMTs to varying degrees (see Table 9.1 below). Our findings suggest compartmentalization was essential to study informants because of the stigma associated with having an invisible chronic illness such as fibromyalgia. Through compartmentalization, informants were able to enjoy privacy in a safe environment occupied only by others who could relate to their daily struggles with fibromyalgia.

For instance, concerning the compartmentalization affordance: on the Reddit SMT, users were able to create throw-away accounts to post private content that they may not necessarily want to be associated with their main profile. If not, every post made in every subreddit using an account could be seen and viewed by anyone with internet access. While on the Instagram SMT, users could create a separate account for carrying out their illness management needs. This finding further unpacks the visibility affordance (Treem and Leonardi 2012) noted by previous scholars because compartmentalization allowed these users to apply selective visibility for different audiences based on their level of comfort in discussing illness related issues. Moreover, the compartmentalization affordance extends the notion of structure proposed by previous scholars who suggest that SMTs could guide chronically ill users to a pre-filtered set of illness-specific information (Merolli et al. 2015). Taking this idea further, compartmentalization affordance allows users to carry out and engage in illness management practices in a separate space from their other activities on the examined SMTs.

Thirdly, our study demonstrates that the examined SMTs afforded storytelling to varying degrees and findings show that these informants could openly discuss all aspects of their lives to varying degrees of support (see Table 9.1) based on the material
features of the SMT. Of course, the extent of a user’s storytelling depends on their decisions concerning anonymity, privacy and their health condition. Nonetheless, the study informants could narrate their experiences through images, texts, videos using SMTs to share their positive or negative experiences with understanding others in the same community. Storytelling in this study supports narration affordances (Bernardi 2016; Merolli et al. 2015) reported in previous studies. Those studies had suggested that narration/storytelling served to foster a shared experience of illness and offer opportunities for chronically ill users to learn from the experiences of others in the same community.

Further, the present study suggests that narration/storytelling is influenced by the features of the technology artefact under consideration. For instance, storytelling on YouTube was quite immediate and personal due to the intimate nature of video-based communication; Reddit supported storytelling by allowing users to create text-based posts. Conversely, it was observed that Instagram appeared to be applied more playfully through posting of memes to illustrate the humorous aspects of life with fibromyalgia.

The next affordance found in this present study relates to sensemaking, another shared affordance that allowed members of these communities to collaboratively solve illness-related challenges through conversations on these SMTs. In YouTube, affordance relied on the capabilities of video creation and commenting, while on Facebook, key informants could make a post, others in the community would comment, and as a community this allowed them to make sense of their illness. This finding adds to previous research that suggested that SMTs afford users meta-voicing (Majchrzak et al. 2013), the sensemaking affordance is a result of the consolidation of multiple users opinions pooled together to solve a problem. (Treem and Leonardi 2012).

The last two identified affordances concern: creative outlet affordance and considered participation affordance. In the present study, SMTs offer chronically ill users a creative outlet, supporting supports creative expression for its users through meme creation and videos. The creative outlet affordance was identified in three cases: YouTube, Instagram and Facebook. Those three SMTs support study informants hedonic needs to engage in creative activities to communicate information support and raise awareness about fibromyalgia. Our study suggests that the examined SMTs
enable their creative expression to different extents (see Table 9.1) this affordance helps maintain a sense of well-being despite the physical and mental toll that Fibromyalgia takes on sufferers.

Our findings also point to the notion of considered participation affordance. The examined SMTs allows its users to interact to different extents based on their current needs (Refer to 9.2.2). As discussed earlier, study informants could engage in tentative, reactive or proactive appropriation pattern; the examined SMTs did not enforce interaction with others on its users. Instead, considered participation enabled members to remain in the SMT environment without the pressure to interact with others. This affordance was especially crucial because it allowed informants control over their activities on the examined SMTs while allowing access to information and emotional resources to help their personal illness management practices. This affordance agrees with the concept of adaptation proposed by previous scholars who noted that SMTs allow chronically ill users to adapt their interactions with others based on their personal circumstances (Merollì et al. 2015).

9.4.2 SMT features that disrupt appropriation for chronic illness management practices

The present study also identified two constraints which could disrupt illness management practices for the study informants which were: emotional overload and misinformation. Therefore, this study makes its final proposition:

**Proposition 10:** Some SMT technology features (such as notifications and newsfeed) could have deleterious impacts on the well-being of chronically ill adults resulting in negative emotional/psychological and illness task related outcomes.

First, emotional overload constraint refers to the bombardment with negative content that was experienced by some key informants on the community-oriented SMTs (Reddit and Facebook). Our findings suggest an imbalance between positive and negative posts on the community-based SMTs (Reddit and Facebook). Due to the mental repercussions of suffering from a stigmatized chronic illness, some key informants on the Reddit and Facebook were negatively affected by the constant need for emotional support from others on these SMTs. For example, there were many posts about potential suicides or to rant and vent to others in the safe space provided by SMTs. Accordingly, some informants in the Reddit and Facebook case study reported feeling overwhelmed, hopeless and depressed by the constant barrage of depressive
posts. A reason for this lies in the design of Reddit and Facebook. These SMTs serve notifications to community members about every new post submitted in the community and could serve to create a negative atmosphere.

During the study, the researcher witnessed some incidents where community members exit the group because they were unable to continue to remain in such negative spaces. This finding unpacks the triggered attendance affordance (Majchrzak et al. 2013) from previous studies to contend that the constant notifications and updates from the group served to disrupt the achievement of positive illness management outcomes. This study shows that the triggered attendance afforded by the notifications and newsfeed features of SMTs like Reddit and Facebook may disrupt appropriation because of the overwhelmingly negative streams of content these individuals are exposed to. Moreover, emotional overload was also a consequence of trolling behaviour as noted in the related findings chapters, where individuals in the community may witness or get into arguments with others in the community which could result in disappropriation (see Chapter 4, Section 4.3.1 and Chapter 7, Section 7.3.1).

Finally, the present study suggests that misinformation constraint could disrupt positive illness management outcomes. While these SMTs could serve as a safe place to collectively make sense with others about illness-related concerns, the present study also suggests that the examined SMTs may also constrain illness management through misinformation. In the present study, misinformation was found to derive from scammers/spammers trying to take advantage of the desperation of these individuals. Further, despite the good intentions of other chronically ill adults in the community, there was a potential to receive bad/dangerous advice because the experience of fibromyalgia is highly individual. However, study informants shared that they were aware of this potential for harm and made sure to discuss each piece of advice received from others in the community with the GPs, especially if it concerned medication.

The appearance of this constraint varied significantly between the examined SMTs. First, participants on community-based SMTs like Reddit and Facebook appeared to manage misinformation through the involvement of other chronically ill users in the community. Reddit and Facebook chronically ill users seemed to be vigilant to dubious content posted in the online group concerning bad advice, miracle cures and spam. As a result, the incidents of misinformation were minimized although
spammers and scammers worked around the group by sending private messages to intended victims. Although misinformation was not directly observed or discussed by informants from the YouTube and Instagram studies, our observations reveal the existence of several accounts about fibromyalgia cures by others in the community. Those posts ranged from accounts selling cures to accounts proposing untested holistic medical aids to relieve symptoms.

9.5 HOW DO CHRONICALLY ILL ADULTS ENGAGE WITH AND APPROPRIATE SOCIAL MEDIA TOOLS TO BETTER UNDERSTAND AND MANAGE THEIR ILLNESS?

The overarching research question of the study was posed to fulfill the aim of this study. To reiterate, this study aimed to gain a deeper understanding of how adults with chronic illnesses engage with and appropriate social media tools to better understand and manage their illness. Accordingly, this broad question was demarcated into the research sub-questions that have been addressed in the preceding sections of this Chapter (See Section 9.2, Section 9.3 and Section 9.4). Consequently, this work has identified the unique process for appropriation of SMTs by chronically ill adults and contributed an integrated model that uncovers the distinct patterns of appropriation conducted on a single SMT and extends that insight to parallel appropriation of multiple SMTs for illness management. Further, this work identified and explored the unique supporting and discouraging factors that influence appropriation of SMTs by chronically ill adults. Also, this work addressed enabling and disruptive affordances of SMT features that impact illness management outcomes of chronically ill cohorts.

Consequently, the following ten key propositions were stated to conclude and summarize key insights that were obtained by addressing sub-questions of this research:

- **Proposition 1**: The stigma of chronic illness and a need to compartmentalize illness management practices encourage chronically ill adults to enact a divergent set of appropriation processes to privately engage in illness management practices on SMTs.

- **Proposition 2**: Chronically ill adults may persist in an appropriation pattern (static) or may switch between different appropriation patterns (dynamic) on a given SMT based on their evolving illness management needs.
• **Proposition 3:** The perceived value of an SMT supporting an adaptive appropriation pattern is that it mitigates the challenges encountered by chronically ill adults when applying the technology artefact for their illness management practice.

• **Proposition 4:** Parallel appropriation of multiple SMTs enable chronically ill adults to develop a toolkit to better support more comprehensive illness management practices based on the different features and capabilities offered by multiple SMTs.

• **Proposition 5:** Chronically ill adults appropriate SMTs to become more knowledgeable about their illness and overcome the disparity of care which enhances their self-management practices, leading to improved health outcomes.

• **Proposition 6:** Appropriation of SMTs by chronically ill adults reduces the emotional/psychological repercussions such as shame that arise from the stigma of having a chronic illness.

• **Proposition 7:** Chronically ill adults are able to obtain increased knowledge of and access to financial aid to support their illness journey, such as useful information on obtaining disability schemes through appropriation of SMTs.

• **Proposition 8:** The characteristics and design of publicly available SMTs support the illness management activities of chronically ill adults because these technologies do not enforce strict usage contexts.

• **Proposition 9:** Some SMT technology features (such as groups features, emoticons) empower chronically ill adults to achieve positive illness management outcomes by providing necessary affordances to address the specific emotional or task-related needs for daily illness management.

• **Proposition 10:** Some SMT technology features (such as notifications and newsfeed) could have deleterious impacts on the well-being of chronically ill adults resulting in negative emotional/psychological and illness task related outcomes.
9.6 SUMMARY

In this chapter, the practice lens of the study has been extended to expose unique SMT processes and influences on appropriation in the context of chronic illness management based on the synthesis of findings from the multiple case study (see Chapter 4- Chapter 7). First, the chapter unpacks the processes for appropriation of SMTs by chronically ill adults. This chapter harnessed findings to explicate a new integrated process model that outlines the appropriation process and supporting or discouraging factors for appropriation of SMTs. Moreover, a new framework is also discussed to explain the plethora of positive and negative influences arising from personal factors, SMT community factors and the SMT technology which influence appropriation for illness management. Furthermore, this chapter provided a set of six enabling affordances identified within the case studies; the chapter also identified two constraints which serve to disrupt positive appropriation outcomes among the study informants. Finally, each of the outlined sections in the discussion culminated in a set of ten propositions that address the study questions. The next Chapter concludes this present study by providing a summary of the research findings and also presents the study implications. Further, Chapter 10 addresses the limitations and future directions for this present study.
Chapter 10: Conclusion

INTRODUCTION

This thesis sets out to gain a more in-depth insight into how adults with chronic illnesses engage with and appropriate social media tools to better understand and manage their illness. The previous chapter (Chapter 9) provided an in-depth discussion of findings from the present study to provide specific insights on the appropriation of SMTs by chronically ill adults. Appropriately, this Chapter concludes the present work by summarising the study conducted and reflecting on significant findings from this research project. This Chapter 10 abstracts from the specific details of the conducted study to consider the implications of this present work against the broader IS context. The remainder of the chapter is structured as follows: the next section offers a summary of the research undertaken, presented in Section 10.1. Next, Section 10.2 presents the implications of the present study. Next, section 10.3 presents the contributions of this thesis to theory and practice respectively. Following that, section 10.4 outlines the limitations of the research. Finally, Section 10.5 outlines potential areas for further study motivated by the conducted work.

10.1 RESEARCH SUMMARY

Several health organizations have warned about the growing incidents of chronic illness and the rising mortality rate that is estimated to result from this global threat (Dadgar and Joshi 2018; Department of Health 2012; Yach et al. 2004). Further, recent studies indicate that chronically ill adults increasingly utilize SMTs as part of their illness management efforts to aid self-management of their illness. To understand the cumulative knowledge on social media appropriation, the researcher conducted a literature assessment which included the rich history of appropriation scholarship in IS. The conducted review showed that IS scholarship has produced several important process theories such as TAM, AST, to provide a holistic picture of appropriation and describe how users may employ an IT artefact to accomplish a given task. The majority of the literature that has examined the process of appropriation of an IT artefact has been conducted in an organizational setting on older technologies such as Notes (Orlikowski 1999) or (Majchrzak et al. 2000). Our review also evaluated related
studies on social media applications in different contexts such as for healthcare and in organizations. Findings from the literature showed that the majority of literature in this area had been focused on influences in terms of a user’s motivations or external factors that affect the use of SMTs particularly in the organizational domain. Another area that previous research has focused on were sociomateriality or affordances that different SMTs provided users in different contexts such as chronic illness management (Bernardi 2016; Merolli et al. 2015; Pousti et al. 2014), social networking (Leonardi 2013; Majchrzak et al. 2013; Riemer and Johnston 2012; Ulmer and Pallud 2014) and emergency coordination (Vaast et al. 2017). Further, our review indicates a paucity of studies that have examined the processes of appropriation of SMTs. As a result, there was limited understanding to bridge insights from traditional IS scholarship on appropriation to the social media context especially concerning SMT appropriations outside an organizational setting.

Our review acknowledges that recent studies have contributed significant theoretical insights on the adoption and use of SMTs. Yet, the review showed that there is currently a fragmented picture on the process, influences and potential impact that arise from the appropriation of SMTs (Refer to Chapter, Section 2.6 for a summary of identified limitations). Consequently, scholars from several disciplines have called for more multidisciplinary investigations to build a theory on who these individuals are, the influences on SMT use and what the patterns of use are by these people (Agarwal et al. 2010; Fernández-Luque and Bau 2015; Fichman et al. 2011; Rozenblum and Bates 2013).

Based on these gaps, the central research question that guided this study was:

*How do chronically ill adults engage with and appropriate social media tools to better understand and manage their illness?*

Moreover, three sub-research questions were formulated based on the central research question:

1. What are the processes undertaken by chronically ill adults to appropriate social media as part of their illness management practices?

2. What factors influence appropriation of social media tools by chronically ill adults?
3. How do social media technology features enable or disrupt illness management practices of chronically ill adults?

The research applied a practice lens that integrated concepts from technology appropriation, social support theory and theory of affordances to scaffold the analysis and interpretation of findings. The first theory in our practice lens was the Model of Technology Appropriation (MTA) served to provide concepts such as technology features and subjective norm which have been reported by previous studies as influential factors on adoption or use of an IT artefact. MTA also provided a generic scaffold to examine processes involved in appropriation or disappropriation of a technology which includes initial encounter, evaluation and stable use of a technology (Mendoza et al. 2010). The practice lens also included Social Support Theory (SST) to account for individual factors which have been reported in similar studies on chronically ill adults as personal influences on participation in online communities or SMTs (Cohen and McKay 1984; Lakey and Cohen 2000; Pousti et al. 2014; Shumaker et al. 1984; Wang et al. 2017). Finally, we included the theory of affordances to reflect the possibilities for illness related actions offered by SMTs. Affordance theory has been applied by related studies to account for potentials for goal-oriented actions provided by an IT artefact for specific cohort (Bernardi 2016; Gibson 1986; Merolli et al. 2015; Treem and Leonardi 2012).

Moreover, the present study was designed as an interpretive multiple case study with mixed methods, to provide a complete picture of the research findings while preserving the voice of study informants (see Chapter 3, Section 3.4). Chapters 4-7 presented findings from each case study, and then Chapter 8 provided a cross-case synthesis which presented unique and general themes found across the multiple case studies. Chapter 9 presented a comprehensive discussion which considered our findings in the light of the practice lens to evaluate confirmations and extensions to the practice lens in Section 9.1. Based on our findings, the outcomes of the present work are:

- A new integrated process model of social media appropriation (Refer to Chapter 9, Section 9.2),
• A new framework of factors which support or discourage appropriation of social media by chronically ill adults (Refer to Chapter 9, Section 9.3), and

• A set of affordances provided by SMT technology features and structures which enable or disrupt chronic illness self-management (Refer to Chapter 9, Section 9.4).

Finally, insights from this work led to the specification of ten key propositions to address the main research question and appropriately fulfil the aim of this study. Thus, this work contributes a deeper understanding of how and to what extent chronically ill adults appropriate social media to better understand their illness.

10.2 SUMMARY OF FINDINGS AND STUDY IMPLICATIONS

Based on the case studies conducted in Chapters 4 - 7, Chapter 9 presented a new integrated process model for the appropriation of SMTs by chronically ill adults (See Chapter 9, Figure 9.1), a new framework of influences on appropriation (Refer to Chapter 9, Figure 9.2) and, a set of affordances that enable or disrupt appropriation outcomes (Refer to Chapter 9, Table 9.1). The new process model presented in Chapter 9 described and explained the processes involved in the appropriation of SMTs by chronically ill adults. Further, the new process model identified appropriation patterns which are unique to SMTs and which may be carried out in appropriation of a single SMT or may include multiple SMTs in a process we denoted as “parallel appropriation”. Next, the framework developed in Chapter 9 identifies and explains supporting and discouraging influences on appropriation of an SMT. The developed framework presented in Chapter 9 was informed by MTA and SST, hence our findings extended these two theories. The third product of this thesis was a set of affordances that were identified as enabling or disrupting positive illness management outcomes.

This thesis provides an integrated, holistic picture of SMT appropriation in the context of chronic illness. The conducted work lies in the intersection of sociotechnical scholarship and sociomateriality to leverage the strengths of both waves of IS research (Gaskin et al. 2014). In doing so, the present work pushes IS scholarship past an organizational setting and opens the hitherto under-explored black box of social media appropriation processes in the public context (Winter et al. 2014; Yoo 2010). This thesis aligns with previous studies in the IS technology appropriation domain which
have focused on adoption, adaptation, technology use and appropriation (Carroll et al. 2007; DeSanctis and Poole 1994; Leonardi et al. 2016; Markus and Silver 2008; Mendoza et al. 2010; Orlikowski 1992; Treem et al. 2015; Vaast et al. 2017). The conducted work is also relevant to work conducted using sociomaterial perspectives to study the processes involved in appropriation through various terms such as entanglement, imbrications and embodiment (Leonardi 2013; Majchrzak et al. 2013; Scott and Orlikowski 2014; Vaast et al. 2017). Furthermore, the present work contributes to the growing discourse on social media and similar technologies which are diffused first in the public and then in organizations. By doing so, it adds to the growing discourse on the role of technologies like social media for managing chronic illness (Agarwal et al. 2010; Bernardi and Wu 2017; Fichman et al. 2011; Wang et al. 2017).

10.2.1 Process of SMT appropriation

Because users of SMTs act through the technology during appropriation, this thesis suggests that appropriation in an SMT context involves complex interactions between a user and the SMT technology artefact. Still, this thesis shies away from the idea of highly localized accounts of appropriation processes such as entanglements, imbrications, embodiments as are reported in recent sociomaterial studies (Leonardi 2011; Schultze 2011; Scott and Orlikowski 2014). Instead, this present thesis suggests that the processes involved in the appropriation of an SMT are unique to the capabilities of an SMT and the user’s task, but can be generalized to similar technologies (Gaskin et al. 2014). Further, this work suggests specific appropriation processes unique to a single SMT and or for parallel appropriation of multiple SMTs which are discussed below.

Single SMT appropriation processes

The present work suggests that because appropriation is task-oriented, the appropriation for illness management purposes is distinct from typical interactions with SMTs. The present work suggests that illness management triggers a different set of activities by chronically ill adults such as searching for and joining communities where they may receive illness management resources. Accordingly, each SMT had a different level of support for this set of actions; for instance, Instagram supported this through the multi-profile function that allowed users to compartmentalize discrete environments separate from their default SMT account. In contrast, on Facebook users
may join closed or private groups specific to their fibromyalgia needs. A key driver for these distinct appropriation activities was the influence of privacy and desire for a safe-space due to illness stigma or fear of alienating friends and family. This study identifies a set of patterns carried out by users to appropriate a single SMT which include: tentative, reactive, proactive and adaptive patterns of appropriation. Tentative pattern relates to actions that enable passive interaction with the SMT community. Tentative actions allowed access to valuable illness management resources, allowed users to receive information, emotional support and allowed these users to learn rules or norms by observing others. This finding is in line with some previous studies which had discussed the value of lurking on SMTs for health (Chung 2014; Han et al. 2014).

This work takes this further to suggest reactive appropriation pattern. The reactive appropriation pattern denoted in this study concerned actions such as liking, downvoting or upvoting content posted by other members of the SMT community. Reactive appropriation allows users to show support or disapproval to content while also giving them a façade of privacy. Through reactive appropriation pattern, users could draw attention to posts, if they felt unable to provide the requested advice and could convey emotional support or acknowledgement. This finding extends previous work which had been conducted on older technologies and had identified two processes of lurking and participation (Chung 2014). The third pattern concerns proactive appropriation which consists of actions like posting and commenting. The proactive pattern served to generate conversations in these communities and also facilitated the exchange of information support, emotional support and solicitation of material support.

This thesis also suggests adaptive appropriation pattern on a single SMT. Adaptive appropriation in the present study was identified on YouTube and Reddit case study. For example, users in the Reddit case study applied web browser plugins to augment the functionality of Reddit. Similarly, YouTubers made use of an array of tools like video editing software, cameras, donation websites like patreon.com to work-around the limitations imposed by YouTube features or policy. This thesis suggests that adaptive appropriation occurs when an SMT is considered valuable but difficult to use. Therefore, users may bring other technologies into their appropriation practice to work-around perceived technological limitations. This set of findings is in line with and extends the adaptation class of studies in past information systems.
research by demonstrating workarounds in the context of social media appropriation (Majchrzak et al. 2000; Sun 2012).

Our findings show that users may vacillate between the four appropriation patterns. This finding is in line with some previous studies that note that stabilization is not a final phase in appropriation (Mendoza et al. 2010). Rather users may move from stabilization, back to evaluation based on changes in technology features. Still, this present thesis suggests that in the SMT context, there is no stabilization phase because these technologies are in a constant state of development (Kallinikos et al. 2013). Taking this idea further, this thesis suggests that appropriation processes of SMTs by chronically ill adults fluctuate based on their health needs or changes in the community.

**Parallel SMT appropriation processes**

This study also suggests the parallel appropriation of multiple SMTs. Parallel appropriation of SMTs involves utilizing a suite of technologies alongside each other to carry out different facets of a user’s task. Because public SMTs are free to use and there is a vast ecology of SMTs with different features, functions and capabilities, users may adopt several in tandem for use in illness management. For example, SMTs like YouTube helped create a brand, generate financial support, allowed intimate interactions with others through video-based self-presentation. Image-based SMTs like Instagram allowed posting of memes or sharing short videos to raise awareness. Community-based SMTs like Facebook or Reddit provided a community where individuals could exchange information and emotional support. This work suggests that parallel appropriation allows the development of an illness management toolkit based on the core capabilities of the technology artefact and the audience on each SMT platform.

**10.2.2 Influences on SMT appropriation**

This thesis suggests that influences on adoption and use of an IT artefact in a public setting differs from influences reported by traditional IS scholarship. The forces at play in an organizational setting such as explicit or implicit mandates to use a technology artefact are not present in the public setting, particularly as concerns chronic illness management. Rather, individuals with chronic illness are driven to
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adopt and use an SMT due to factors related to maintain emotional/mental health and obtain necessary resources to manage the daily task of illness management.

**Task and emotional influences on adoption and use**

Moreover, the present work argues that the diagnosis of chronic illness acts to trigger a distinct set of appropriation activities from default social networking. Users join or create illness specific spaces to obtain resources necessary to manage their health. Information support in this study allowed users to collectively make sense of their illness through collaboration with others on the SMT environment. Through interactions in SMT communities chronically ill users can gain access to resources such as coping strategies of others in the community and treatment plans of other chronically ill members of the community. This aspect sheds further light and extends theoretical insights on the role of SMTs in reducing disparities in care provision as proposed by some other studies (Agarwal et al. 2010; Goh et al. 2016). It was clear from the study that individuals made use of information derived from SMT interactions in their daily health practices, during consultation with medical practitioners and to learn more about their illness. Through these factors, individuals could become advocates for themselves with their GPs and gain better care. This thesis puts the practice of managing one’s illness into the context of task-technology fit literature because chronic illness management is a lifelong task.

Additionally, managing psychological well-being is a necessary part of illness management for chronically ill users (Dadgar and Joshi 2018; Wang et al. 2017). Especially when dealing with a complex poorly understood “invisible illness” such as Fibromyalgia. Fibromyalgia is a challenging comorbid illness that often occurs with other conditions such as chronic fatigue, depression, pain induced insomnia or anxiety. This work identifies and explains the role of emotions for adoption and use of an SMT in the context of chronic illness management. While other studies had taken the view that emotional influences on adoption and use of an IT artefact arise from the user’s reactions to IT events. This view is standard in the adaptation class of studies which had examined emotional factors that influence adaptation during disruptive IS events (Beaudry and Pinsonneault 2010; Ortiz de Guinea and Webster 2013; Stein et al. 2015; Yang and Bahli 2015).

The present work suggests that emotional needs could occur before adaptation to an IT and drive appropriation of an IT artefact. In the present study, users had to
cope with the adverse emotional effects of chronic illness through the adoption and use of SMTs. Negative emotional factors found to influence the adoption and use of SMTs in the present study include illness stigma, isolation, loneliness, frustration, shame. The positive emotions found in the present study that arose from adoption and use of SMTs include validation, acceptance, belonging and empathy. Thus, this thesis supports and extends the stress and coping literature because these emotional factors act as a buffer from the negative repercussions of suffering an invisible chronic illness such as fibromyalgia (Barrera 1986; Lazarus 1993; Shumaker et al. 1984). Another aspect from the present thesis that extends stress and coping literature is the idea of social support being a sub-component of emotional support, rather than a distinct concept. The function of creating friendships and relationships (social support) was conducted in this environment because of the need to connect with understanding others.

Another significant finding concerned the material/monetary incentive that influenced the adoption and use of SMTs by some individuals from the YouTube study. This work suggests that in the context of chronic illness, financial support exchanges take place and serve as an influencing factor for adoption and use of SMTs. Recall that our study informants who were unable to maintain jobs as a result of their illness. Through the adoption of SMTs, they were able to engage in different activities that led to financial support exchanges. For example, learning from others on how to file a disability pension claim, donating to other members of the community through other websites like gofundme.com, selling fibromyalgia related products like books, t-shirts, mugs and attempting to gain direct financial support by YouTubing. This work supports the initial premise of SST that suggested material support as a benefit derived from social support exchanges. We contrast with empirical studies in the social media context that have overlooked influences of material support on SMT adoption by chronically ill adults (Pousti et al. 2014; Wang et al. 2017). This study suggests that factors such as usefulness which are immediately apparent in traditional IS studies are more indirect in SMTs (Davis 1989; Mendoza et al. 2010). Instead, users in the public context describe usefulness in terms of the value of SMTs to accomplish their tasks such as illness management. Accordingly, this thesis extends previous studies on usefulness to indicate how its meaning differs between a utilitarian organization context and in the context of public, voluntary SMT adoption. Therefore, the present
work suggests that future IS studies in the public context should strive to unpack perceived usefulness in terms of value-fulfilment for different cohorts.

**The structuring effects of an SMT environment**

It is essential to acknowledge that established factors in previous IS studies such as purchase cost of SMT may serve as an influence on the adoption of SMTs given that social media technologies in the public context are freely available, accessible on multiple devices and free to use. This aspect confirms and extends previous literature on adoption and diffusion of technology innovations (Davis 1989; Rogers 1995; Venkatesh et al. 2012; Venkatesh et al. 2003). Further, this thesis suggests that SMTs are a flexible technology which does not have a specific use context inscribed on them (Alaimo and Kallinikos 2017; Kallinikos et al. 2013). Most publicly used SMTs are designed to be easy to use, to facilitate adoption by diverse cohorts with different usage needs. Ease of use was apparent in all cases except the YouTube case. Nonetheless, through the other members of the community, this factor was mitigated to an extent because they were able to obtain unofficial help through videos and posts made by other community members.

In contrast to some studies that have argued against the idea of scholars allocating structuration capabilities to technology artefact (Orlikowski 2000), this work suggests that technology can be a source of structure. Especially in the context of modern SMTs where users act through technology interacting as profiles. First, to access communities of similar others on SMTs, users are limited based on the technology capabilities of an SMT. For instance, community formation on sites like Reddit or Facebook could be explicitly created with a virtual description, location and explicit membership.

Conversely, SMTs such as Instagram or YouTube do not have explicit community creation capabilities. Instead, community formation takes place by following a hashtag, an account or a channel and community participation was carried out by commenting on content. This aspect supports previous literature on the roles of technology as a source of structure (DeSanctis and Poole 1994; Orlikowski 1992).

Taking this further, we argue that aspects of SMTs such as technology features and usage policies exert a significant influence on how SMTs are applied to chronic illness management. Recall that in the public context, users have no control over the
feature updates that are rolled out for the SMTs they adopt and use for illness management. Therefore, users continuously adapt and structure their practices to the technology-as-designed before adapting to SMT technology-in-practice. Accordingly, this study extends and supports recent studies which have ascribed agency to technology artefacts using various lens such as sociomaterial theorizing (Orlikowski 2007; Treem and Leonardi 2012; Vaast et al. 2017). This thesis also suggests that factors such as subjective norm are experienced through technology because interactions between chronically ill adults are carried out through the SMT. Our study identified that communities formed on SMTs have rules and roles for its members. For instance, Facebook or Reddit communities have explicitly written rules for the conduct of members. Compliance was enforced by other members of the community regarding issues like trolling, spam posting and scamming. Whereas, SMTs like Instagram or YouTube have implicit rules that moderate the behaviour of members in the ad-hoc chronic illness community. This thesis supports and extends previous studies that have suggested subjective norms as an influential factor on the adoption and use of an IT artefact (Ajzen 1985; Davis et al. 1989; Mendoza et al. 2010; Venkatesh et al. 2012).

Our study also indicates that self-efficacy is related to the roles of members in the community. The self-efficacy finding supports and extends previous studies which had suggested it is an influential factor on technology use (Venkatesh et al. 2003) or social support (Bernardi 2016; Bodenheimer 2002; Lakey and Cohen 2000). Further, this work notes that self-efficacy in this aspect is unrelated to perceptions about technology, rather self-efficacy in the study was concerned with perceptions of expertise and confidence in knowledge about managing fibromyalgia (Bernardi 2016). Our study suggests that roles in SMTs are negotiated based on several factors inclusive of self-efficacy because more knowledgeable members become sources of information to less experienced members of the SMT community.

This thesis further suggests some factors which negatively impact the adoption and use of an SMT. While SMT communities are a valuable resource of illness management, findings also show that they could be a source of factors that negatively influence adoption and continued use through issues like Spam; trolling; community dissolution; harmful emotional content. Spam, trolling and harmful emotional content were observed to a more considerable extent on community-centric SMTs such as Facebook or Reddit. This thesis suggests that these aspects could lead to adverse
emotional outcomes like increased stress and depression leading to disappropriation of an SMT. To that end, this study addresses the body of studies that call for research into the harmful effects of SMT appropriation (Maier et al. 2015; Turel 2015).

10.2.3 Enabling or disruptive affordances provided by SMT tool features

This thesis suggests several ways that SMT appropriation may affect chronically ill adults in terms of affordances which may enable or disrupt illness management outcomes. To reiterate, this present study views affordances as opportunities for goal-oriented action (Gibson 1986; Merolli et al. 2015; Treem and Leonardi 2012). This work suggests that social media allows users to act-through these SMTs for illness management needs and affords a sense of belonging. Belonging to a community of similar others allows users to feel validated, accepted, understood. This finding supports previous studies which had coined the terms association, connection, or building a support network (Bernardi 2016; Majchrzak et al. 2013; Treem and Leonardi 2012). This thesis goes further to suggest that belonging is essential to combat the isolation and stigma of chronic illness. Belonging enables emotional well-being especially in terms of a challenging illness like fibromyalgia. The sense of belonging may be enjoyed through tentative, reactive or proactive appropriation patterns. Other affordances which align with previous studies include storytelling, sensemaking, identity and considered participation (Bernardi 2016; Majchrzak et al. 2013; Merolli et al. 2015; Treem and Leonardi 2012) (Refer to Chapter 9, Section 9.2.3 for the comprehensive discussion and list).

This thesis also suggests that SMTs afford compartmentalization. Through compartmentalization, users could freely vent and discuss the ramifications of their illness in a safe space free from the view of others in their online or offline community who may not relate to their experiences. Compartmentalization was offered to varying degrees on the examined SMTs. For instance, Reddit provided throwaway accounts, while Instagram provided multiple profiles for users. Compartmentalization is crucial to chronically ill adults because it allows private discussions in a judgement-free virtual space. This thesis extends SMT and affordance studies to demonstrate additional affordances which may lead to positive illness management outcomes.

Taking this further, the present work extends this line of research to show dangerous outcomes that may arise from SMT appropriation. In contrast to previous studies which have only discussed enabling affordances from SMT use, this study
suggests that SMTs may have negative impacts on chronically ill adults through disruptive constraints like emotional overload and misinformation. Emotional overload is a consequence of constant bombardment with emotionally charged posts seeking emotional support or discussing suicide. The technology features of SMTs serve users with notifications based on the topics or groups they follow. Fibromyalgia is a challenging progressive condition, and the majority of posts made by sufferers could be depressing and discouraging for chronically ill adults. Another notable constraint is misinformation. Users on SMTs receive advice from other chronically ill adults and may rely on that illness management resource. Yet, there should be concerns about the credibility of some information received because other users on the SMT are not medical professionals. Moreover, there is a significant risk of falling victim to bad advice (fibromyalgia is highly individual), scammer or spam.

10.3 STUDY CONTRIBUTIONS

Findings from this thesis make several contributions to theory and practice which are outlined and briefly discussed below, demarcated as contributions to theory and contributions to practice.

10.3.1 Contributions to theory

This study contributes to theory in the following ways, it addresses calls from several IS scholars who have challenged further research in a real-world context, in contrast to the numerous studies that have been conducted in an organizational setting. This research is significant because it provides theoretical insights to explain SMT appropriation, particularly in the context of chronic illness. Moreover, this thesis provides evidence to contribute to theory in technology appropriation because it:

1. Extends the Model of Technology appropriation to the social media context: This study extends MTA with SST and affordance theory to explain the process of appropriation in a social media context. In this study, there was a clear argument that suggests the processes of appropriation in a social media context differ because the structure of SMTs support unique appropriation processes of multiple SMTs and for a single SMT. Accordingly, the study leveraged insights from the original MTA (Carroll et al. 2007) and its extensions (Fidock et al. 2008; Mendoza et al. 2010) to serve as the central theory to guide investigation on how and to what extent.
combination of MTA, SST and affordance theory served as a useful guide to explain the unique process of appropriation that exists in the public context particularly with new technologies like social media.

2. **Explains the processes of appropriation for chronically ill adults in a social media environment:** This study presents a new process model that explains how and why chronically ill adults appropriate social media tools. Our model is a class II theory, according to the taxonomy proposed by Gregor (2006) which allows the empirical evaluation of social media systems in the context of chronic illness management (Gregor 2006b).

3. **Describes supporting and discouraging influences on appropriation social media tools by chronically ill adults:** This study presents a framework that can be used to evaluate social media tools in the context of chronic illness. This investigation on the appropriation of social media in the context of chronic illness indicates that some core concepts of social support theory serve as incentives for adoption of social media as part of the chronic illness management process. This study contributes to theory because most studies on social support in online communities tend to neglect the influence of technology in obtaining the benefits of social support. This study outlines empirical evidence that illustrates the specific influences that encourage or discourage SMT appropriation.

4. **Identifies affordances which act as enablers or disruptors to social media appropriation by chronically ill adults:** This study contributes to the growing interest on affordance theory and its role in IS, particularly in the social media context. The present study exposes the underlying affordances which act to enable or disrupt chronic illness management.

5. **Explains how different types of social media support illness management needs of chronically ill adults.** This thesis explains how different social media tools are appropriated by chronically ill adults. By so doing, our findings showcase needs that may drive adoption and use of diverse SMTs, the influential factors on different types of SMTs and; the different affordances which may enable or disrupt appropriation across different types of SMTs.
10.3.2 Contributions to practice

One of the main motivations of the study was the lack of empirical evidence that demonstrated how social media technologies are appropriated for chronic illness management. Thus, the practical contribution of this study is the provision of empirical evidence to inform stakeholders such as: healthcare service providers, general practitioners and chronically ill adults on the nature, influences and outcomes of social media appropriation for chronic illness management. Moreover, this thesis provides the following practical contributions:

1. **Provides actionable insights into the potential applications of SMTs to enhance care delivery for chronically ill adults:** The induced process model offers a clear insight into how SMTs are appropriated by chronically ill adults. This model is essential as there has been little research that has explained how social media are used as part of the illness management practices of chronically ill adults. It is crucial for healthcare stakeholders to derive a complete picture of how SMTs are applied for illness management practices to create positive or negative outcomes for chronically ill adults. Our findings could inform the design of specialized SMTs for self-management of chronic illness. Further, in addition to the process model, the researcher provides a set of propositions to summarize and motivate further work based on findings from this work. Accordingly, the process model is especially valuable given the high attrition rate previous research ascribes to similar technology interventions that are designed to aid chronic illness management in the healthcare sector.

2. **Provides an outline to facilitate further involvement of GPs and other caregivers for the day to day practice of chronic illness self-management:** Given the anticipated global increase in chronic disease due to lifestyle factors and an ageing population, our study offers useful insights on how SMTs could augment self-management practices by chronically ill adults and reduce disparity in care provision. The present study showed that SMTs are a valuable resource to chronically ill adults and serve as a space to discuss concerns about medication and coping strategies in a non-judgmental environment of understanding others. Because SMT use for illness management is only expected to increase with time, we suggest that primary care physicians have open discussions with chronically ill adults in their care about the benefits and dangers which have been outlined in the
study at hand. Through open discussion about SMTs in chronic care, GPs can ensure they remain part of decision making for self-care practices by their patients and can intervene when dangerous or incorrect information is provided to these individuals.

3. **Outlines the benefits and risks that arise from the use of different social media tools to inform the self-management practice for chronically ill adults:** Our study also presents useful information for chronically ill adults. SMTs are powerful tools which could provide illness management resources such as supportive social relationships or information support about coping with illness and medications. There is a potential for harm through spam, misinformation and emotional overload because of the constant need for help from others in the community. Therefore, chronically ill adults are advised to consider the risks carefully and involve their primary care physician in this practice to evaluate advice received from the SMTs.

4. **Provides a needs-based assessment and comparison to assist self-selection of SMTs for self-management of chronic illness:** It may serve these individuals to select an SMT based on their illness management needs. Those individuals who need information support resources may benefit from community-based SMTs like Reddit and Facebook because of the significant community membership. Those large communities offer chronically ill adults the opportunity to access a plethora of treatment plans which may assist their education, empowerment and self-advocacy. On the other hand, individuals with severe mental health issues may benefit more from SMTs such as Instagram or YouTube, where there is a more positive atmosphere filled with emotionally uplifting content. Ad-hoc communities such as YouTube Instagram may offer more positive emotional outcomes than the community-based SMTs like Reddit and Facebook which showcase a barrage of emotionally charged content which could be detrimental for mental health.

**10.4 STUDY LIMITATIONS**

Despite the theoretical and practical contributions of our study, it is worth noting certain limitations. A significant limitation is the small number of informants for the qualitative aspect. Because the researcher recruited informants through the examined SMTs, it was difficult to access a higher number of willing participants due to issues
like trust, differing time zones and because users with fibromyalgia experience significant health challenges which could affect their availability. Recruitment was especially challenging for the YouTube case study as the features of YouTube such as the messaging feature, did not provide notifications to its users about the messages we sent to them. Nonetheless, we were able to access enough participants to achieve data saturation, and we complemented the qualitative aspect with data analytics using data derived from the APIs of the examined SMTs to corroborate and complement findings.

Another limitation of the study is that due to the focus on chronically ill adults, it could be claimed that findings are unique to these individuals. The researcher suggests that these findings may be extended to other contexts, primarily due to the multiple case study design applied to conduct this study (see Chapter 3, Section 3.8). Also, studies conducted on SMTs are inherently limited because it was not possible to observe all activities of study informants such as chatting with others or lurking. However, the researcher attempted to mitigate this by asking informants about these actions to obtain richer insights on how the examined SMTs were used by study informants.

The third limitation to the study concerns the retrospective accounts on issues that may be better examined at earlier phases of the appropriation process, as all key informants were already familiar with these SMTs and were current users of each examined SMT. Sampling methods restricted research participants to chronically ill patients who were already regular users of social media site; therefore, the discussions around adoption could be subject to recall bias. Nonetheless, the study cohort consisted of a mixture of informants who had varying levels of familiarity with the SMT.

The final limitation to the study also pertains to under-representation of male participants in qualitative portion of the study. The present study has significantly more female key informants (38 of 42) than male key informants (4 of 42). In addition, majority of study participants were located in the USA. This outcome was not a research design choice, rather it was a consequence of the sampling technique applied to recruit potential study informants.

10.5 FUTURE STUDIES

Based on the contributions of this thesis, several areas deserve further examination in future work. Given the patient centred nature of the present work, the
A perspective of health providers on the SMT phenomenon deserves further study to gain a balanced view on the effects SMT appropriation has on the delivery of care for chronically ill adults. This raises questions such as 1) To what extent does appropriation of SMTs for illness management impact the relationship between a patient and their primary care physician? 2) How do the themes of patient advocacy and empowerment which were found in the present study impact care delivery from the perspective of a GP? Examination of these aspects would contribute a holistic understanding of how best social media tools may be applied to enhance the illness management journeys for chronically ill users and further assist delivery of care.

An additional area that deserves further study lies in the effects of SMT community dynamics on information use by chronically ill adults. As found in the present study community-based SMTs such as Reddit or Facebook were constantly filtering through misinformation or spam to prevent dissemination of dangerous advice which could have dangerous repercussions on others in the community. Future work could investigate the occurrence of misinformation on community-based and ad-hoc SMTs to develop guidelines on how best to protect against these incidents for vulnerable chronically ill adults. Further, a study on that aspect could include the trajectory on how information received for illness management are verified, applied or discarded and to what extent primary care physicians are informed on/included in this process.

Another avenue for further study is adaptive appropriation of SMTs: future work could examine the practice of augmenting SMTs by chronically ill adults. SMTs are experienced as configurations of several technologies. For example, a laptop/pc or mobile device is used to access an SMT web-service via a network connection. It would be interesting to understand the configuration of various technologies that are drawn into the practice of illness management to advance theory on the nature of newer technologies such as social media outside the organizational setting.

Finally, another fruitful area for examination lies in the products from the present thesis which are: a framework of influences, a process model of appropriation and a set of affordances. This work also outlined a set of ten propositions that could serve as a starting point for further study. It is worth investigating to what extent our findings apply to other chronic illnesses such as diabetes, endometriosis or depression.


Business Insider, pp. 3–5 (available at https://www.businessinsider.com.au/how-facebook-was-founded-2010-3#we-
can-talk-about-that-after-i-get-all-the-basic-functionality-up-tomorrow-night-1).


and use of mobile telephones by 16 to 22 year olds,” Journal of Information 
d=12372; retrieved March 23, 2016).

Carroll, J., Howard, S., Peck, J., and Murphy, J. 2007. “From adoption to use: the 
process of appropriating a mobile phone,” Australiasian Journal of Information 

youth of today want?technology appopriation by young people,” in Proceedings 
of the 35th Annual Hawaii International Conference on System Sciences. IEEE, 
pp. 1777–1785.

Conducting Integrative Mixed Methods Research and Data Analyses,” Journal 


Department of Health & Human Services. 2016. “Care for people with chronic conditions: guide for the community health ;,”


Etherington, D. 2016. “Instagram Stories has 100 million daily active users after just 2 months | TechCrunch,” (available at https://techcrunch.com/2016/10/06/instagram-stories-has-100-million-daily-active-users-after-just-2-months/).


Hookway, N. 2008. “‘Entering the blogosphere’: some strategies for using blogs in social research,” *Qualitative Research* (8:1), pp. 91–113 (doi: ...


http://dspace.mit.edu.turing.library.northwestern.edu/handle/1721.1/2742).


Bibliography


Sun, H., Fang, Y., and Zou, H. (Melody). 2016. “Choosing a Fit Technology:


Effect of Paralinguistic Digital Affordances on Perceived Social Support,”


Wolfe, F., Smythe, H. A., Yunus, M. B., Bennett, R. M., Bombardier, C.,


Yin, R. K. 2013. *Case study research: Design and methods Case Study Research*:

Appendix A

Plain Language Statement (PLS)
PLAIN LANGUAGE STATEMENT

Project title: Appropriation of Social Media by Adults with chronic illness

Investigators: Isika Nwakego (PhD Student); Dr Mendoza (Supervisor); Dr Bosna (Supervisor)

Dear Participant,

You are invited to take part in the research project that will form part of the student researcher’s Doctoral PhD thesis, and has been approved by the Human Research Ethics Committee, project number #1646962.1.

The aim of this study is to gain a deeper understanding of how adults with chronic illnesses engage with social media tools to share experiences and connect with others who share the same context. In addition, we would like to examine how social media technologies are used as a tool to aid adults better understand and manage their chronic illness. Findings from this study will lead to uncover specific social media technology aspects that can be incorporated in the design of future supportive chronic illness management tools. Where applicable, we have received permission from the group moderator to contact you (your name and contact details have been provided based on your profile).

Should you agree to participate, you would be asked to contribute in the following ways:

1) We would like to access and follow your posts for 3 months so that we can gain a deeper understanding of how and why you use social media tools to engage with peers and exchange experiences.

2) At this stage we might interact with you if necessary through online discussions to better understand the role of this social media tool in your lived experiences as concerns sharing information, engaging in social activities and the interactions enabled by the use of this tool.

3) In these online discussions, we will also be asking questions concerning your role and observations of the group in relation to how social media aids or hinders your conversations and impact on your lived experiences. Each online discussion will be considered active for a week to allow ample time for participation and discussion. We will also provide a copy of the transcript so that you can verify that the information is correct and/or request deletions.

Once the research project is completed, a brief summary of the findings will be made available to the participants upon application. It is also possible that the results will be presented at academic conferences or published in journal articles.

If you would like to participate, please indicate that you have read and understood this information by signing the accompanying consent form and returning it by email. The researcher will then contact you to arrange a mutually convenient time for you to complete the interview.

Your name and contact details will be kept in separate, password-protected computer files from any of your data we access or that you supply. This will only be able to be linked to your responses by the researchers, for example, in order to know where to send your online discussion transcript for checking. In any of the publications derived from this study, you will be referred to by a pseudonym. We will remove any references to personal information that might allow someone to guess your identity; however, we will be recruiting other members of the group for participation therefore, it is possible that someone

Project HREC 1646962.1, May 15, 2016, Version 1.1
(e.g. others on the site and/or group) may still be able to identify you. This is the possible risk that could arise as a result of participating in the study.

The information you provide will be treated as confidential and used for only research purposes connected with this research project. Confidentiality of the information will be protected, subject to any legal limitations. Access to the information will be restricted to the investigators named above. As required by the University, data will be held in locked or password-enabled cabinets in the Department of Computing and Information Systems, and destroyed using confidential waste disposal techniques after five years following the last publication from the research.

Please be advised that your participation in this study is completely voluntary. Should you wish to withdraw at any stage, or to withdraw any unprocessed data you have supplied, you are free to do so without prejudice. If you have any questions about this research please contact Dr. Antonette Mendoza at: Level 06 Room 6.10, Doug McDonnell Building, Department of Computing and Information System, University of Melbourne, Victoria 3010, Phone: +61 3 83441411, Email: mendozaa@unimelb.edu.au

If you have any concerns regarding the conduct of this research please contact the Executive Officer, Human Research Ethics, The University of Melbourne, VIC 3010 ph: (03) 8344 7507 fax: (03) 9347 6739.

Project HRE# 1646962.1, May 15, 2016, Version 1.1

Department of Computing and Information Systems
The University of Melbourne, Level 8, Room 5, Doug McDonnell Building, Parkville, Victoria 3010
Australia
T: +61 3 8344 1500 F: +61 3 9349 4596
Appendix B

Participant Consent Form

PARTICIPANT CONSENT FORM

Project title: Appropriation of Social Media by Adults with chronic illness
Investigators: Isika Nwakego (PhD Student) Dr Mendoza (Supervisor); Dr Bosua (Supervisor)

PARTICIPANT’S NAME: __________________________________________

I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written plain language statement to for my records. I understand that after I sign and return this consent form the researcher will retain it. I understand that my participation will involve an online discussion, a 25 minute SKYPE interview, analysis of my posted social media content and I agree that the researcher may use the results as described in the plain language statement.

I understand that any information I provide is confidential, and that, subject to the limitations of the law, no information that could lead to the identification of any individuals will be disclosed in any reports on the project, or to any other party.

I acknowledge that:
(a) The possible effects of participating in the interview and analysis of my 3-month posted social media content have been explained to my satisfaction;
(b) I have been informed that I am free to withdraw from the project at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;
(c) The project is for the purpose of research;
(d) I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements;
(e) I have been informed that with my consent the interview will be recorded and I understand that these recordings will be stored at University of Melbourne and will be destroyed after five years of the last publication; I am also aware of the risks of participating in this project;
(f) My name will be referred to by a pseudonym in any publications arising from the research;
(g) I have been informed that a copy of the research findings will be forwarded to me, should I agree to this.

I understand that if I have any concerns about the conduct of this research project, I can contact the Executive Officer, Human Research Ethics, The University of Melbourne, phone: 83442073; fax: 93476739. These details are also provided in the project description.

I agree to be recorded during the interviews □
I wish to receive a copy of the summary project report on research findings □

This consent form will be retained by the researchers.

Signature: ____________________________ Date: ____________________________

(Participant)

Project HRE# 1646962.1, May 15, 2016, Version 1.1

Department of Computing and Information Systems
The University of Melbourne, Level 8, Room 5, Doug McDonnell Building, Parkville, Victoria 3010 Australia

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Appendix C

Sample Interview Questions

Online discussion questions (Facebook)
1. Could you share with me why you joined this facebook group? How did you get to know about it?
   a. When did you join (more or less)?
2. Could you share your reasons for using this facebook group?
3. How has the information shared in this facebook group influenced or not influenced your personal health management practices?
4. How often are you active on this facebook group? How do you participate? And what makes you participate/makes you keep participating in this group? Also, would you classify yourself as, e.g. an Experienced patient, a Transitioning patient, exploring patient or a Newly diagnosed patient.
5. How do you feel while using these facebook groups? Does the group trigger positive or negative emotions for you?
6. Are you active on other social media sites? (If yes, in what capacity and which ones?)
   a. Would you say that you are more active on these sites that this one and why?
   b. Would you mention issues you have and discuss in this group on any of your other sites – why or why not?
   c. How would you describe the communications in this group as compared to the other social groups you participate in? Are there differences in the discussion you have in those groups compared to this group?
7. Which features do you use the most on facebook while communicating with others on this group?
   a. Why do you use these any pros and/or cons?
8. Are there some facebook features you use more than the others? Why those features?
9. In your opinion, how would you describe your role in this facebook group? *
10. Could you describe your interactions with members of this facebook group?
11. How do the features of facebook groups influence your communication with other members of this group? Are there any members of the group that you communicate with outside of facebook? Why?
12. How would you describe the value of this group to your personal life?
Appendix D

Sample Field Notes

On YouTube, it seems that the users lurk for years after becoming aware of the platform. Some things that could influence this behavior:

- The technology of YouTube allows consumption of created content without any requirements to join.
- The users could be exploring the features of the technology and getting accustomed to the social norms of the community.
- Initial strangers due to being new to the community could cause users to be hesitant to actively participate.
- Among the behaviors I noticed, lurking is followed by creating an account and then liking and commenting.
- Content creation seems to be influenced by some degree by the community's acceptance or rejection of a member.

Interestingly, it seems that the users migrate from one platform to another based on the prompts of the social media influence or key member.
Appendix E

Screenshot from data analytics strand

Figure 10.1 Screenshot of Data analytic strand using Jupyter notebook IDE